

**THE DESIGN AND EVALUATION OF A KNOWLEDGE  
TRANSLATION TOOL FOR PREGNANT SOUTH ASIANS AND  
THEIR PRIMARY CARE PHYSICIANS:  
USING A SCALABLE APPROACH TO ADDRESS A PUBLIC  
HEALTH CHALLENGE IN A PRIORITY POPULATION**

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PREGNANT SOUTH ASIANS AND THEIR PRIMARY CARE PHYSICIANS:  
USING A SCALABLE APPROACH TO ADDRESS A PUBLIC HEALTH CHALLENGE IN A  
PRIORITY POPULATION

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TITLE: The design and evaluation of a knowledge translation tool for pregnant South Asians and their primary care physicians: using a scalable approach to address a public health challenge in a priority population

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## Abstract

This study, which is focused on addressing the rising prevalence of gestational diabetes mellitus (GDM) in South Asians begins from the perspective that the development of diabetes has scope across public health and anthropology. The onset and progression are rooted within social determinants of health and cultural practices. Similarly, pregnancy—which is a crucial component of the life course—is a time where not only nutrients are shared between mother and child, but also when knowledge is exchanged, and cultural ways are imparted to the pregnant person from their friends and family. Within the South Asian community of Southern Ontario, recent public health evidence demonstrates a high rate of GDM where 1 in 3 South Asians will develop the condition. Babies born to GDM mothers are of higher birthweight and percent body fat than those of non-GDM mothers. Interventions to prevent GDM are important because GDM itself is a risk factor for postpartum obesity, diabetes, and atherosclerosis in the mother, and also because infants with more adipose tissue are more likely to become insulin resistant in adolescence and develop diabetes and cardiovascular disease as adults.

Discussions to strengthen the public health response to this challenge can incorporate evidence-based counselling tools (e.g., easily scalable knowledge translation (KT) tools) that can be used by prenatal clinicians providing primary care. Given that diet and physical activity can be influenced not only by an individual locus of control, but also by familial interactions/networks and cultural/traditional foods and expectations, there is a need to better understand and weave in these experiences. I sought to better understand 1) the prenatal lifestyle counselling experiences of South Asians and their family doctors; and 2) the KT tools that have been designed and used in this population; then I used these learnings to develop and evaluate a theory-informed, evidence-based KT tool for pregnant South Asians and their family physicians.

This dissertation begins with an introduction of patient and provider experiences with lifestyle change. I then present a systematic review and narrative synthesis of prenatal KT tools designed for South Asians. This is followed by a case report that outlines the process taken to develop a patient-facing and provider-facing KT tool ('SMART START'). Next, I include the design and evaluation of a mixed methods pilot evaluation study of 'SMART START.' Finally, I culminate with an epilogue that ties in lessons learned and challenges that were overcome throughout the conduct of this work. The concluding chapter also includes a link to a video that captures the story behind this dissertation and the documentation of how all the aforementioned pieces are nested within and built upon one another.

## Acknowledgements

*This thesis is dedicated to my little one, Kalden Reese Kandasamy Pamunuwe.*

Kalden, I hope one day when you can read and understand the words in this dissertation, that you too can appreciate how grateful I am for your support during the last few years. I know that some days Amma had to choose writing over going to the park; she had to choose meetings over playtime and quick lunches over long games of *hide and seek*. Amma knows that you too sacrificed a lot for us to stand together this way in the summer of 2021. You have been my inspiration throughout this whole process and sitting here reflecting on this has only made it more apparent to me. Thank-you for keeping me true to why I am on this journey in the first place. A PhD is a certainly a steppingstone to many other possibilities, but with this responsibility, I promise to be honest, transparent, and aligned with the values of community. I promise not to limit myself to the ivory tower. I promise to intentionally form connections. To meaningfully form bridges. To thoughtfully form long-lasting partnerships between academics and community members so that we may evoke change together, hand in hand. My motivation for doing this work comes from a place of hope—I want you to grow up in a world where you are celebrated as a person of colour and the healthcare system stands to its potential. And from that, I hope you work in a space that allows you to make positive contributions, recognize and adapt to emerging challenges, and do it with wholehearted intentions. Thank-you Kalden for the sacrifices you have made so that Amma can achieve one of her goals.

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Finally, to my sister. My guardian angel. Since you passed in 2011, I have been on a journey to find purpose and joy again. Completing this dissertation was an important goal of mine and has truly helped me cultivate personal and professional collaborations, purpose, and even joy. I know you would be proud...



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## **LIST OF ABBREVIATIONS**

BiB: Born In Bradford Cohort

BCC: Behaviour Change Communication

CADTH: Canadian Agency for Drugs and Technology in Health

CanMEDS: Canadian Medical Education Directions for Family Physicians

CONSORT: Consolidated Standards of Reporting Trials

CVD: Cardiovascular Disease

GDM: Gestational Diabetes Mellitus

KT: Knowledge Translation

KTA: Knowledge-To-Action Framework

PNMS: Pune Maternal Nutrition Study

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

START: South Asian Birth Cohort Study

T2DM: Type 2 Diabetes Mellitus

WIDER: Workgroup for Intervention Development and Evaluation Research

## Declaration of Academic Achievement

This thesis is a “sandwich thesis,” which combines three individual projects published, submitted for publication, or prepared for submission in peer-reviewed journals. All three projects are original pieces of work that I conducted. I am the first author and primary contributor of every manuscript contained in this dissertation. A supplementary multi-media project that ties together my dissertation through the documentation of my process conducting these projects (end-of-study dissemination video) is enclosed as a link in the final chapter. The following descriptions detail my contributions in all the chapters of this dissertation.

**Chapter 1:** Part A, B, and C are unpublished works. Sujane Kandasamy is the sole author.

**Chapter 2:** This chapter is published in the *Canadian Journal of Diabetes*. Sujane Kandasamy is the first author (shared co-first authorship with Linda Nguyen). Russell de Souza conceptualized the study. Sujane Kandasamy, Dipika Desai, and Russell de Souza organized focus groups, individual interviews, and collected all data. Sujane Kandasamy and Linda Nguyen analyzed the data with guidance from Russell de Souza, Diana Sherifali, and Sonia S. Anand. Sujane Kandasamy led the writing of the manuscript with Linda Nguyen. All authors agreed on the final version of the manuscript.

**Chapter 3:** This chapter is prepared for submission to *Healthcare for Women International*. Sujane Kandasamy is the first author, having led the project, data collection, analysis, and writing of the final manuscript.

**Chapter 4:** This chapter is prepared for submission to the *Journal of Patient Experience* as a *Case Report*. Sujane Kandasamy is the first author and takes ownership of curating the evidence and writing the final manuscript.

**Chapter 5:** This chapter is prepared for submission to the *Canadian Journal of Public Health*. Sujane Kandasamy is the first author, having led the project, data collection, analysis, and writing of the final manuscript.

**Chapter 6:** This concluding chapter is unpublished. Sujane Kandasamy is the sole author. The supplementary film, which is prepared to be uploaded using a public-facing platform (e.g., Youtube) was produced in collaboration with a South Asian artist (Soumbal Qureshi, who created the digital illustration) and film-maker (Bhavna Samtani, who was involved with filming and editing the final piece).

## **CHAPTER 1: INTRODUCTION OF THE THESIS**

## Note to the Reader

Reflexivity is a crucial component in the process of generating knowledge by the means of qualitative research methodologies (1-4). These conversations, which are positioned within a broader debate about ontological, epistemological, and axiological components of the self, are important areas of focus for qualitative researchers. Understanding the role of the self in the creation of knowledge, self-monitoring the impact of personal perspectives, beliefs, and experiences on research, and maintaining the balance between the personal and the universal are fundamental aspects of quality. In particular, positional reflexivity leads the researcher to explore place, biography, self, and other to better understand how they mould and shape the analysis. Thus, reflexivity, which is awareness of the influence of the researcher on research participants and/or the topic being studied also includes understanding how the research topic is in turn impacting the researcher (5). Reflexive engagement throughout the course of research (design, conduct, analysis, writing) is important in maintaining continuous engagement between the researcher's subjective responses and the dynamic research process. Within a constructivist paradigm, reactivity is not seen as problematic, it is instead a critical component of co-creating knowledge (3). The interviewee is always "present in the object" (6), and the researcher is always "written into the text" (7). In this sense, the researcher and the participants co-create the encounter and research actually becomes a collaborative construction of knowledge instead of uncovering the knowledge already assumed to exist. This is important to work through and share because criteria for qualitative rigor emphasizes the relational aspects of knowledge construction (e.g., transparency, reciprocity, critical self-reflection). To delve into the crucial components of my positionality through this work, I have prepared the following compilation that discusses my intentions, biography, and how my positionality has changed over the course of this work.

*My experiences planning, executing, and writing the pieces of this dissertation have been full of positive energy and learnings. There was no way I could have achieved my goals without a team of mentors who have guided me, not only methodologically and analytically, but also on how to thoughtfully inject the intrinsic curiosity for arts-based approaches that circulate through my blood stream. Combining the sciences with the arts has been a lifelong goal of mine and to be able to weave together these two fields within my dissertation has been a true pleasure. Furthermore, being a South Asian (Tamil) Canadian woman, working on addressing a public health challenge in my own community, has been an even deeper pleasure. My professional passion for working at the intersection of gestational diabetes and South Asian health originates from a narrative that weaves through my personal life. My mother, who was diagnosed with gestational diabetes when she was a new immigrant to this country, later went on to develop type 2 diabetes, a condition that she has been managing daily for the past two decades. Looking for answers in this space that surpasses elements of literacy (language and health based) was not only a professional goal, but also a personal one. This is because my interest in equitable health communication was shaped through the interweaving of my own family's lived experiences and previous professional experiences that unequivocally illustrated the importance of community engagement and culturally-tailored avenues for knowledge translation.*

*I would also like to acknowledge how my position changed throughout the conduct of this work. I went from being the "researcher" to the "researched." For most of my graduate career (i.e., from MSc, which I began 2013), I have been interested in women's health, particularly pregnancy. Pregnancy is an important phase in the life course because of the potential*



*opportunities and motivations around improving or sustaining one's lifestyle (diet and physical activity). When I conducted the work around understanding the barriers to and facilitators of lifestyle change among pregnant South Asians and their healthcare providers (Chapter 2), the systematic review (Chapter 3) and the design of the KT tool (Chapter 4), I was approaching my work as a semi-outsider. I could identify with many of cultural nuances within the South Asian community (e.g., traditional foods, understandings of physical activity), but I had never experienced pregnancy, given birth, or raised a child. While embarking on my final study, the evaluation of the KT tool (Chapter 5), my role as a researcher changed slightly. It was in January of 2019 (just as the study's ethics approval was being attained), that my partner and I found out we were expecting our first child. I was grateful for the gift and very excited for the opportunity to be a mother! Being a pregnant South Asian woman, recruiting other pregnant South Asian women completely altered the optics of my work, but also flipped the switch on me being an empathic researcher to me being a sympathetic one. I began to better understand the cultural expectations (as I too was in the process of curating personal experiences of this); I could better assess the resonance of the messages, images, and ideas that were portrayed in the tool; and, I was able to approach participant interviews with a different level of understanding. Wearing the hat of "researcher" and "researched" helped me build better connections with research participants, be better attuned to some of the challenges associated with recruitment and data collection, and participate in a unique way when it came to data analysis. It was almost like I had these raw "gut checks" with myself before, during, and after each research decision. With this being said, I also recognize that each individual's experiences are unique and specific to their own upbringing and circumstance, and as someone who has been fortunate enough to not experience certain life challenges (e.g., barriers related to language preferences and healthcare system navigation, etc.), I am not able to perfectly "wear the hat" of any research participant. However, being South Asian and also in a similar "biological boat" as these research participants helped me build trust in ways that otherwise would not have been possible. This would have directly and indirectly contributed to the level of engagement (including candor in interview responses). Furthermore, wearing the hat of a non-physician researcher placed me in a disadvantageous place with study design (as I was not coming to the table with lived professional experiences of prenatal counselling), however, it may have played to my advantage when aiming to build safe environments for data collection.*

*As documented by others, studying members of a community to which one personally belongs has both advantages and disadvantages. For example, Chew-Graham et al., 2002 describe that when interviewing someone who is a member of the same profession or known to the interviewer in professional circles, recruitment and access may be simpler, yet prior knowledge can directly influence how the researcher is seen, the kind of information that is offered, and the way that data may be interpreted (8). Because of shared professions, interviewees may presume that the researcher shares similar viewpoints. This can either result in participants being more open, (leading to more genuine data) or, in comparison, cause them to contend, try to impress, or collude with the researcher in "a case of shared conceptual blindness" (8; page 288). This opens the discussion for an interesting intersection, where sharing similar ethnic and biological background may help to build trust and simultaneously, not sharing similar professional background can do the same. From time to time, I also shared examples of my own reflexivity with participants, and although one can never eliminate social desirability bias, responses from participants that suggested the interviews were a healing experience, especially during the*

*COVID-19 lockdown when social interactions were limited, was certainly an indication of frankness.*

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## Part A: Outline of the thesis

The *life course perspective* describes the interaction between biological and environmental exposures during the different stages of life (e.g., pre-pregnancy, pregnancy, infancy, adolescence, adulthood) and how they impact health outcomes (1). When considering obesity and other cardio-metabolic conditions, evidence indicates that exposures during early development (e.g., pregnancy, childhood) can impact the development of obesity later in life (2). Studies in ethnic groups demonstrate that unique ethnic-specific differences exist in maternal health behaviors (3), the prevalence of gestational diabetes mellitus (GDM) (4,5), birth weight (4), postnatal growth (3), and the development of overweight/obesity and associated metabolic risk factors (6). Among South Asians, the rates of GDM are high (1 in 3) and require public health interventions (5) to prevent downstream complications and healthcare system burdens. This dissertation includes the key information that contributes to the understanding of how to develop, design, create, and evaluate a scalable, multi-media intervention (Knowledge Translation (KT) tool) to strengthen the response to this emerging public health challenge.

Each subsequent chapter is nested within the previous chapter. To carry forward the *life course perspective*, I will weave the discussion of Matryoshka dolls (or more commonly known as nesting dolls) as a design paradigm to better explain how these chapters are nested within each other. Nesting dolls are associated with family and fertility. They are representations of the mother-child relationship, often seen as mothers carrying on the family legacy through their child in their womb. This thesis relates to women's health, pregnancy, empowerment, and wellbeing throughout the life-course. It represents nuggets of information, evidence, and experiences that are essentially "nested" within each other. Metaphorically, the "Matryoshka principle" denotes an identifiable relationship of "objects within similar objects." I hand-painted the following four nesting dolls to

represent each step of this dissertation (see Figure 1). After coming across the use of this design principle in other academic settings to describe complex relationships (e.g., 7), I became interested in crystallizing the analogous arms within the contexts of life-course epidemiology and KT science and practice. As a metaphor, it aligns closely with the general concept of nesting (i.e., pregnancy), mother-child relationships, knowledge transfer, and the features of nesting ideas within each other.

1) The smallest doll (baby) represents the evidence. It is a collection of systematic reviews, rigorous birth cohort studies, and local needs assessments that make up the core elements of this dissertation. These research efforts are represented by the magnifying glass that is hand-painted on the back of the doll. This is the backbone of Chapter 1 (part B and C) and Chapter 2.

2) The second doll (child) represents the nesting of this evidence into a tool, which is the product that is used to engage communities of interest. The respective KT tool ('SMART START'), which was developed as part of this dissertation is represented by the wrench that is hand-painted on the back of the second doll. This is chapter 3.

3) The nesting of the evidence and the KT tool is done so in the third doll (adolescent), which represents the efforts taken to evaluate the tool. The evaluation of the 'SMART START' KT tool using a mixed methods pilot study approach is represented by a bull's eye target that is hand-painted on the back of the doll. This is chapter 4.

4) The final doll (adult) represents the concluding remarks and cohesive presentation of the entire dissertation via the nesting together of all the previous dolls (i.e., end-of-study KT, the way that we package and present the entirety of this work to a scientific audience and back to the communities of interest). We use the symbol of an audience to represent the nesting of all the aforementioned items into the final adult doll. This component is included in chapter 5.



Figure 1. Hand-painted nesting dolls that represent the salient components of this dissertation, as they are nested within one another: the evidence, the development of the KT tool, the evaluation of the KT tool, and the final end-of-study KT piece.

The first chapter will set the stage by describing the theoretical framework from which I position this dissertation, defining what I mean by ‘South Asian’, and a discussion of cardiometabolic risk factors in the South Asian community (including the high prevalence of GDM cases among South Asians living in Peel Region, Ontario, Canada). I also present a brief overview

of why and how knowledge translation is important within this context, making a case for knowledge translation tools as an important facet of public health practice and health promotion.

In the second chapter I present a local needs assessment conducted to understand the perspectives of pregnant/recently pregnant South Asian parents and prenatal clinicians. In this study, we use qualitative methodology (interpretive description) to better understand the perspectives and experiences of currently/recently pregnant South Asian women and prenatal clinicians as it relates to lifestyle modification in the prevention of gestational diabetes. From this work, we reiterate the current public health challenge of 1 in 3 South Asians developing GDM and introduce new ideas for contemplation as we embark on designing and implementing new interventions: 1) individual locus of control, family networks/supports, and cultural factors (e.g., traditional foods) are important considerations from the perspectives of pregnant South Asians; and 2) insufficient resources, time, and logistical challenges are the most salient barriers for prenatal clinicians.

The third chapter will present a systematic review and narrative synthesis describing the depth and breadth of KT tools that have been designed for pregnant South Asians. Studying the components of KT tools targeting this population may allow for a better direction on future intervention design, development, and evaluation. As a summary, the search strategy generated 1054 titles and abstracts after duplicates were removed; post title/abstract screening and full text assessment, 11 studies were included in the final narrative synthesis. We report on the general and specific features that contributed to intervention acceptability: 1) *general features* of a) trusted tool delivery; b) the packaging of empowering, motivating, and myth dispelling evidence-based health messages; c) simple, structured, co-ordinated, and visually reinforced design that has been pilot-tested; and 2) *specific features* that are particularly nuanced for this population such as a)

increasing trusted delivery by using female voice artists (to emulate trusted and amicable female relatives); b) integrating family-centric messaging; c) adapt designs to local practices, cultural factors, and use familiar melodies to supplement audio-visual material. These nuggets can be implemented in future tool design to improve uptake among South Asian communities. Interesting, none of the studies described tools that were developed or evaluated in countries outside of South Asia. With some of the concepts expressing transferability to high-income countries, the subsequent chapters that describe the design and evaluation of a KT tool for South Asian pregnant women in Southern Ontario, Canada help to fill the gap associated with this limited data.

The fourth chapter will address the theoretical and empirical work that embeds the design of a new scalable KT tool designed for pregnant South Asians and delivered by trusted family physicians ('SMART START'). KT tools can empower patients to make healthy lifestyle choices when they weave together theoretical frameworks with empirical work that includes local need (patient experiences), contextual considerations (theory), and arts-based designs (engaging elements). The description of how we established the 'SMART START' KT tool is intended to be used as a case study for developing a timely KT strategy that addresses a public health challenge in a priority population. The sharing of lessons learned are included to help guide other researchers on a similar journey of improving patient experiences within prenatal settings.

In the fifth chapter, I describe the process taken and the results of evaluating the 'SMART START' KT tool in two real world settings: family medicine clinics in Mississauga, Ontario, Canada. We use a mixed methods pilot study to randomize and evaluate the feasibility and acceptability (primary outcomes), and in a very exploratory way, evaluate the change in knowledge, attitudes, practices, and confidence (secondary outcomes) of the 'SMART START' KT tool in comparison to standard care prenatal resource provision in primary care.



In the sixth and final chapter, I review and summarize the learnings from these projects. In addition, I indicate and expand upon the key obstacles that I overcame during the conduct of this work and points of triumph that can be built upon as future directions of this work. This discussion includes strengths, limitations, and implications for research, clinical practice, and policy.

Overall, this work is approached from the position that the onset and progression of cardiometabolic risk factors and disease has anthropological and public health dimensions (i.e., the course of disease is patterned by cultural practices and social determinants of health). Social ecology theory views health practices as being influenced by many levels: intrapersonal, interpersonal, organizational, community, society, political—and interventions that span across these levels are likely to be more effective (8). Glass & McAttee theorize a ‘stream of causation’ where behaviour and disease risks are influenced across the life course (9). This model brings together the social and behavioural arms within the context public health. Beginning upstream (in utero, early life exposures) we move downstream (later life exposures). Nested within are a hierarchy of systems that range from *genes* to *cells* to *organs* to *the psychology of behaviour* to *social networks* to *local society* to *global environment*. Within the context of GDM, which is a growing global public health challenge, has roots in complex individual behaviours, genetics, and environmental factors. Focusing solely on individual behaviours may be costly and produce limited results. In addition, upstream environmental, social, and cultural factors play important roles in shaping behaviours that relate to food selection and gestational weight gain. These relate to community-level factors (e.g., built environment), food availability (e.g., access to grocery stores, cost of food, etc.) and preferences (e.g., Traditional foods, Western foods, hybrid alternatives), and workplace conditions (e.g., work schedules, workload/responsibilities). Although all the elements of this approach were not addressed in this dissertation, the intention

was to better understand the key elements that can help support South Asian parent's journeys through navigating early-life GDM prevention through a public health approach that prioritizes individual behaviours, community factors, and cultural practices.

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## Part B: Background

*South Asians:* Several different definitions of ‘South Asian’ exist in Canada. Examples of these definitions are based on language, religion, and geopolitical boundaries. Statistics Canada defines South Asian as those who self-identify as having ancestral origins in South Asia (i.e., from the Indian sub-continent, which includes the regions of India, Sri Lanka, Pakistan, Nepal, and Bangladesh). ‘South Asian’ is thus a collective term that describes a culturally, religiously, and linguistically heterogeneous group.

South Asians are the largest and fastest growing ethnic group in Canada, making up more than 5% of Canada’s population (approximately 2 million) (1,2). The largest communities of South Asians currently live in Ontario (Toronto, Peel), British Columbia (Vancouver), and Alberta (Calgary, Edmonton). Over 67% of South Asian Canadians live in the Metro Vancouver and Greater Toronto areas (3,4). It is projected that by 2031, over 55% of Canada’s foreign-born communities will report origins in Asia (5). Canadians from South Asia may also choose to identify by their countries of origin (e.g., Indian, Pakistani, Bangladeshi), mother tongue (e.g., Punjabi, Tamil), or religious beliefs (e.g., Hindu, Sikh, Muslim). For diaspora communities, the selection of how one chooses to define or classify their identity is a personal journey and may be rooted in family history, culture, or migration experiences.

*Early-life determinants of cardiovascular disease among South Asians:* Originally proposed by epidemiologist David Barker, the “Barker Hypothesis,” postulates that intrauterine growth restriction, low birth weight, and premature birth are causally associated with the onset of hypertension, type 2 diabetes (T2DM), and coronary artery disease later in life (6). *The Pune Maternal Nutrition Study (PMNS)* being one of the largest cohorts in India, provided the foundation for how maternal dietary practices impact fetal growth and diabetes (7). Findings from

the PMNS cohort show that South Asian newborns have lower birthweights, but similar visceral adiposity compared to White European newborns from the United Kingdom (8). The Born in Bradford (BiB) Cohort, which aims to better understand the environmental and genetic determinants of health in South Asians living in Bradford, United Kingdom, also demonstrated that South Asian newborns have a lower mean birthweight compared to White European newborns, which increases their risk for several other cardiovascular morbidities later in life (e.g., obesity, metabolic syndrome, type 2 diabetes) (9,10).

Nutrition is an important environmental factor that has known influences prenatally, in infancy, and early childhood. In low-income countries, the risks are predominantly due to undernutrition, whereas in higher-income countries (e.g., Canada), the risk for overnutrition (excess calories but undernourished) is higher. This unbalanced state is associated with adverse maternal, infant, and child health outcomes, including excessive gestational weight gain, gestational diabetes (GDM), slow or rapid postnatal growth, childhood adiposity, and allergies.

GDM is a condition where a pregnant woman without previous diabetes develops high blood sugar levels (11). It is a strong risk factor for T2DM, as over 50% of women diagnosed with GDM develop T2DM within 5-years postpartum (12,13). These women also face a seven-fold higher lifetime risk of T2DM compared to women who were not diagnosed with GDM (14-17). Markedly, T2DM is also predictive of future cardiovascular disease (CVD) in the mother and increases the risk of T2DM in the offspring up to eight-fold (14,16,18-21). Evidence from our South Asian Birth Cohort (START), a prospective approach to understand the genetic and environmental risk factors of metabolic disorders in South Asian women and their offspring, shows that 36.3% of South Asian women in Ontario develop GDM (22). Similar to PMNS, START has also demonstrated that South Asian newborns in Canada have significantly lower mean

birthweight and higher skinfold thickness (adiposity) compared to White Europeans, which has been associated with higher maternal glucose and adiposity (23).

Prenatal development is an important component that may help explain the etiology of adult diseases. During this period, the fetus is exposed to many influences such as nutritional availability, maternal endocrinological disorders, and environmental factors, leading to early life “programming” (24, 25). This programming can also be influenced by GDM, which results in extra glucose and growth hormones being passed from mother to fetus. The fetus is thus exposed to a hyperglycemic state (i.e., increased insulin demand) (26). The resulting increased fetal adipose tissue has been postulated to catalyze the development of the “thin-fat” phenotype (27). The “thin-fat” phenotype is described as lower birthweight infants with higher adiposity, which is common of children born to South Asian mothers (28). This relationship is thought to persist for at least one generation or longer and even in conditions of adequate nutrition (23, 29).

Many different factors influence birth weight. These include gestational weight gain, maternal pre-pregnancy weight, maternal height, GDM, fetal smoke exposure, and maternal dietary intake (30-33). The investigation of specific foods and nutrients have advanced our understanding of nutrient deficiency syndromes (e.g., folic acid and neural tube deficiency) (34) and harmful food components (trans fats and cardiovascular disease) (35). Recent investigations of dietary practices in South Asian populations have advanced our understandings of the impact of dietary patterns (e.g., plant-based diet and increased birth weight) and high/low quality foods associated with GDM development (36, 22). Next steps include pairing this work with new qualitative investigations to better understand culturally-tailored nutritional advice and prospects for interventions, knowledge translation, and scalable public health efforts.

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## **Part C: Knowledge Translation: a guiding discussion**

Within this discussion of GDM, culturally-relevant public health interventions and health promotion efforts, it is important to bring in a short but vital dialogue around the role of Knowledge Translation. Knowledge Translation (KT) is a broad field of study where many different terms have been used to describe the overall process of moving knowledge into action (1). In fact, in 2009 McKibbon et al., identified over 100 different terms describing the use of evidence-based knowledge (2). In Europe, the terms ‘implementation science’ and ‘research utilization’ are commonly used; in the USA, ‘dissemination and diffusion,’ ‘research use,’ and ‘knowledge transfer and uptake’ are common; and in Canada, ‘knowledge translation’ has been adopted through the mandate of the Canadian Institutes of health Research (CIHR), the federal agency for the funding of health research in Canada. Defined by CIHR as a “dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the healthcare system” (3). The common theme across these terms and definitions moves from simple dissemination to establishing intentional avenues for knowledge application. Within the field of KT, there are four core competencies: 1) Understanding the models and frameworks of KT; 2) Capacity for systematic reviews that address KT questions; 3) Use of qualitative methodologies to examine factors that influence the use of evidence; and 4) Capacity to evaluate the impact, effectiveness, and sustainability of KT strategies (4).

KT interventions encompass a broad array of individual, organizational, and structural strategies and approaches to bridge gaps between the research-practice process (5). KT tools are a subset of these interventions that present research evidence in user-centric languages and formats to provide recommendations or to meet knowledge needs (6). As resources and products, KT tools

are created to simplify complex information, improve patient and clinician knowledge, and facilitate the movement of knowledge to practice. They are particularly suited for lay audiences and hypothesized to engage, foster, and empower ‘effective consumers’ who are better suited to participate in informed health decisions (7). One of the important facets of this process is to simplify and enhance evidence-informed information exchange between clinicians and patients in ways that prioritize patient values, perspectives, and experiences. KT tools can be clinician-centered (e.g., clinical practice guidelines) or patient-oriented (lay-language educational resources, videos). Importantly, two systematic reviews have demonstrated that patient-mediated KT interventions should be paired with interventions targeting practitioners (e.g., training) to increase effectiveness (8, 9). The dual nature of this approach has been demonstrated to improve patient perceptions of health professionals' adoption of shared decision making in routine clinical practice (8). The development and evaluation of KT tools involves active collaboration between methodologists, content area experts, and those with lived experiences (i.e., end users) (1) and careful tool development should also include usability testing and mixed method evaluations (10). The incorporation of Arts-based KT (ABKT) strategies are increasingly becoming viable means of deeper engagement by providing evidence-based products and tools in palatable, culturally-tailored, and lay-language formats (11,12). These approaches combine non-academic modes of communication such as digital media (e.g., videos, short films, infographics) and artistic expressions (e.g., story-telling) to re-dress traditional KT outcomes such as changes in knowledge, attitudes, and behaviour modification practices (13). These approaches can be operationalized by 1) identifying goals/target audiences; 2) choose genres, mediums, and methods for examining impact; 3) building partnerships with artists and communities; and 4) tracing dissemination and impact of ABKT (14).

Theory-informed and evidence-based KT tools are possible avenues to help strengthen the public health response to the rising cases of GDM. As knowledge, family/friends, and economic factors are considered the most common barriers associated with GDM prevention (15), it is important to consider KT tool development using user-centric approaches that prioritize patient and family engagement in behaviour change decision-making. Conducting a local needs assessment to better understand specific knowledge gaps and barriers/facilitators to information exchange can be a first step in designing more effective, relevant, and practical tools for a specific group or population.

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## **Chapter 2**

**Formative qualitative work (needs assessment) to understand the barriers to and facilitators of lifestyle changes to prevent gestational diabetes in South Asian parents**





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**DIABETES  
CANADA**



## Original Research

# Barriers to, and Facilitators of, Lifestyle Changes to Prevent Gestational Diabetes: An Interpretive Description of South Asian Women and Health-Care Providers Living and Working in Southern Ontario, Canada



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## Key Messages

- 1 in 3 South Asian women living in Ontario will develop gestational diabetes mellitus.
- Adopting healthy diet and exercise patterns is facilitated by considering an individual's locus of control; ensuring emotional and family support and cultural awareness.
- Insufficient resources, time and logistic challenges were barriers to lifestyle counselling expressed by care providers.

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## ABSTRACT

**Objectives:** People of South Asian ancestry are the fastest growing non-Caucasian ethnic group in Canada and are at high risk for developing type 2 diabetes and coronary heart disease. Pregnant South Asian women have a 2-fold increased risk of developing gestational diabetes, which increases their risk of type 2 diabetes and coronary heart disease. The specific objectives of this study were to explore the perceptions of health behaviours (diet and physical activity) during pregnancy in the South Asian community.

**Methods:** We used interpretive description to further understand the cultural and contextual factors that influence the knowledge, attitudes and practices of diet and physical activity of South Asian women of childbearing age and those who provide health care to this group.

**Results:** Two major themes that emerged from the perspectives of 10 South Asian pregnant women included: (1) importance of considering an individual's locus of control; and (2) support (emotional and information exchange) from family, friends and health-care providers. Two major themes identified by the 11 health-care providers were: (1) cultural awareness in caring for South Asian women during pregnancy; and (2) clinic management, logistics and resources. A common theme for both South Asian pregnant women and health-care providers was the importance of considering the cultural landscape in relation to how knowledge is obtained, shared and valued.

**Conclusion:** A better understanding of these cultural underpinnings may support the development of interventions tailored for pregnant South Asian women and their health-care providers.

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## INTRODUCTION

People of South Asian origin are the fastest growing non-white ethnic group in Canada and are at high risk for developing type 2 diabetes and coronary heart disease, often up to 5 to 10 years earlier than other groups (1,2). Our recent systematic review found that elevated levels of blood glucose and coronary heart disease are 2.5 times more prevalent in South Asians, compared to white Europeans living in Canada (3). South Asian women are also 2.3-fold more likely to be diagnosed with gestational diabetes (GDM) during a singleton pregnancy than the general, non-Asian population (7.7.% vs. 3.3%) (4,5). GDM is a condition in which a woman without diabetes develops high blood sugar levels during pregnancy. Babies born to GDM mothers are of higher birthweight and percent body fat than those of non-GDM mothers (6). These findings are important because GDM is a risk factor for post-partum obesity, diabetes, and atherosclerosis in the mother (7), and because infants with more adipose tissue are more likely to become insulin resistant in adolescence and develop diabetes and cardiovascular disease as adults (6). Interventions that promote a healthy pre-pregnancy weight and improve diet quality have the potential to prevent GDM among South Asians living in high-income countries, such as Canada where this condition is more prominent (8).

Systematic reviews find that non-pharmacological trials to encourage lifestyle changes during pregnancy (including multidimensional coaching (9,10), intensive dietary counselling (11,12) and/or physical activity (13) are few, often not randomized, and are heterogeneous with respect to design and outcomes (14,15). When analyzed together, however, the results are encouraging. Our network meta-analysis (21 trials during pregnancy; n=1,865 women) found reduced glycemic load and/or increased fiber intake with appropriate gestational weight gain advice improved fasting glucose levels (16). In another meta-analysis (44 trials; n=7,278 women),

diet modification alone (3 trials; n=409 women) reduced incidence of gestational diabetes (relative risk [RR]: 0.68; 95% CI: 0.48 to 0.96) (17). However, none of these studies were in a Western-migrant South Asian population. One trial of diet to prevent GDM in India has been published, but is not directly relevant to the Canadian context, as it enrolled women living in slums in Mumbai (18). These data highlight the importance of understanding barriers and facilitators to healthy active living in pregnant South Asian women living in Western-migrant contexts before rigorously testing dietary interventions in the population.

A UK study identified that many South Asian women experience pregnancy as a stressful and difficult period, perceiving exercise and diet restrictions to worsen specific symptoms such as tiredness (19). When presented with a diagnosis of GDM, pregnant South Asian women identified challenges understanding their diagnosis and implementing lifestyle modifications (20). Finally, many women believe that excessive eating, such as the belief of “eating for two” is necessary to gain strength for the mother and fetus (19,20). They expressed fear that a GDM diagnosis meant greater restriction of their traditional dietary habits and difficulties preparing appropriate food (20).

An intervention to prevent GDM can influence multiple behaviours, and thus must be designed with full consideration of the multiple roles that a woman has, such as wife, mother, sister, patient, employee, and supervisor (21). Interestingly, women are likely to engage in lifestyle changes during pregnancy because they are considering their own, as well as their growing baby’s health. Therefore, interventions specifically designed for women during pregnancy might be helpful to facilitate lifestyle changes. Furthermore, better understanding the barriers and facilitators to diet and exercise in this higher risk group can help us learn more about how we can design successful interventions and suggest recommendations that can improve clinical practice.

The objective of this study was to understand current clinical practices and barriers to and facilitators of healthy active living behaviours from the perspectives of healthcare providers and recently pregnant South Asian women, respectively. The results of this study will inform recommendations to improve clinical practice and the design of future interventions for this population.

## **METHODS**

### ***Guiding Analytic Framework***

To better understand the perspectives of pregnant South Asian women, it is important to understand how their views are shaped by the South Asian cultural landscape. For over 60 years, the *Culture Care Diversity and Universality* theory has been one of the most widely used frameworks for understanding meaningful care in diverse cultures (22,23). Leininger developed the *Sunrise Model* to present a holistic view of the different dimensions of care and how they interrelate to individual practices (24).

This theory and model focuses on the culture of individuals, families, subcultures, groups, communities, or institutions (23). Culture is defined as “a lifeway of a group with values, beliefs, norms, and patterns that are learned” (24). Culture strongly influences individual and community values and beliefs, especially during pregnancy. Thus, a better understanding of how culture shapes these relationships is an integral component to the development and implementation of behaviour modification strategies. Researchers must be open-minded and learn from participants without imposing their own ideas and data should be considered from a holistic viewpoint (23). Models and theories can be used as a lens to explore potential components that may influence the study methodology and findings (25). In our study, the Sunrise Model was used as a guiding

framework to understand culturally-based factors that influence the healthcare and practices of pregnant South Asian women. Specifically, we are interested in how these cultural factors impact clinical practice and influence diet and physical activity modification to prevent GDM.

### ***Study Design***

Ethical approval for this study was received through the Hamilton Integrated Research Ethics Board (Project #1219). Our inquiry uses an interpretive descriptive approach to understand and analyze key patterns of factors that influence nutrition and exercise from the perspectives of recently pregnant South Asian women, and healthcare providers that care for this population. The goal of interpretive description, which has roots in phenomenology and ethnography, is not to overly theorize the findings, but instead to generate practical solutions for challenges faced by patients and healthcare professionals (26). This study used a constructivist research paradigm to co-create knowledge with research participants (27). The approach we used generates knowledge by describing the factors that influence the behaviours we wish to learn about (i.e. barriers and facilitators to lifestyle change) and to interpret responses for the purpose of clinical understanding and meaning. We sought to assess the relevance of this knowledge for healthcare providers in the South Asian community. To ensure applicability in practice, a multi-disciplinary and multicultural research team designed the study, developed the methods, and collected, reviewed, and analyzed the data. Disciplines represented by our team include: nutritional epidemiology, dietetics, nursing, behavioural psychology, health research methodology (qualitative methods), allopathic medicine, and rehabilitation science. Specifically, SK, LN, and DD are doctoral-level research students with formal training and expertise in qualitative research methodologies within various health settings; SSA is a physician-researcher who specializes in the cardiovascular disease risk factors in various

ethnic groups; DS is a registered nurse-researcher and diabetes educator focusing on evidence-based diabetes practice and the implementation and evaluation of strategies for diabetes self-care at the patient, provider and population levels; RD is a registered dietitian and nutritional epidemiologist who studies dietary risk factors for chronic disease. The various cultural backgrounds represented by the team also allowed us to bring diverse perspectives to the study design and data analysis in order to come to purposeful and meaningful conclusions. We developed the interview guide in a way that would help us inform practice change recommendations and lifestyle modification interventions designed for pregnant South Asian women.

### *Participant Recruitment*

#### *Sample*

Pregnant or recently pregnant women of South Asian ethnicity (defined as ancestry from India, Pakistan, Bangladesh, or Sri Lanka) were eligible, as were healthcare providers (i.e. dietitians, nurses, and physicians) who counsel women of this background irrespective of their own ethnicity. We used several approaches to recruit our purposive sample of South Asian women and healthcare providers. First, members of the research team had well-developed professional networks of physicians, dietitians, and nurses who recommended and/or reached out to colleagues. Second, from those connections, we used a snowball sampling technique where participants recommended others who met eligibility criteria (28). Snowball sampling was used to recruit both women and healthcare providers). Third, we worked with several health organizations in the Peel region to recruit women and healthcare providers. When working with organizational partners on recruitment, we first met with leadership to discuss the details of the study. Afterwards, they reached out to women and healthcare providers and arranged the interview and/or focus group with

interested participants. In the cases where professional networks or snowball sampling were used, we contacted participants directly by phone, provided information about the study, and scheduled an interview depending on their availability. Financial compensation was not provided to participants for any component of this study.

### *Setting*

The Peel region is a part of Southwestern Ontario in which a large proportion of the population is of South Asian ethnicity (40%). Interviews and/or focus groups were conducted based on the preferences of each participant, taking place either at the participant's home, over the phone, or in a private clinic room. Private clinic rooms were used in the cases where we partnered with other healthcare organizations to recruit women and/or healthcare providers for focus groups. These focus groups were held in rooms located within the organization's onsite facility and were provided in-kind (e.g., local community centre, endocrinology clinics, etc.). The setting allowed participants to share their perspectives in an open, safe, non-judgmental, and confidential environment.

We ensured that participants provided verbal and written informed consent prior to the interviews and/or focus groups. We also reiterated during the interviews and/or focus groups that participation was voluntary and that any information shared would remain confidential, as long as responses did not indicate that participants, for themselves or others, were in any harm.

### *Data Collection*

Data collection and data analysis occurred concurrently, which is consistent with an interpretive description approach (29). The interviews and focus groups were semi-structured,

which provided an opportunity to modify questions as the themes began to emerge from the data. We structured and implemented interviews and focus groups with pregnant and/or recently pregnant participants to allow them to freely discuss their beliefs in a comfortable setting, facilitated by a female South Asian interviewer (SK and/or DD). The interview guide included questions designed to elicit beliefs regarding optimal health behaviours, with a focus on diet and physical activity, for a woman before and during pregnancy. We developed probing prompts to elicit perceived facilitators and barriers to changing behaviours. Interviews and focus groups were conducted with healthcare providers who self-identified as counselling pregnant South Asian women in their respective practices. These interviews were conducted by female South Asian interviewers (SK and DD) and a healthcare professional (RJD) using a semi-structured interview guide that inquired about current clinical practices, challenges, and barriers to and facilitators of lifestyle counselling. Questions were modified within an iterative process to probe about preliminary themes that were identified (See Appendix A for the semi-structured interview guides used with women and healthcare providers).

### ***Data Analysis***

We conducted all interviews and focus group discussions in English. Native languages were used by a fluent speaking interviewer (DD) to further clarify questions and responses as necessary. We audio-recorded the sessions, which were then translated and transcribed verbatim. We entered and analyzed text of the sessions using NVivo-11 (QSR International, Australia) (30), a program designed to manage and support the analysis of qualitative data. Mother and healthcare provider data were analyzed in parallel using different coding frameworks. We used an inductive process to analyze interviews and focus group discussions (31), described as follows. Two research



team members (SK and LN) initially coded the first transcript independently and formulated the analytic codebook together. The initial codebook was modified based on a discussion with the full research team to incorporate multidisciplinary perspectives. Using the codebook as a guide, SK and LN independently coded all remaining interviews. Frequent discussions were held with the research team about the coding analysis to add or combine codes and identify key themes. These debriefing sessions helped determine the number of additional interviews required to consolidate data in order to suggest recommendations for clinical practice. Data collection and analysis occurred iteratively and concurrently (29). Group discussions were held to reach an agreement that the themes were described in sufficient detail to understand our clinical phenomenon of interest as it relates to the facilitators and barriers to lifestyle change among South Asian pregnant women (32). We assigned pseudonyms to participants for the purpose of sharing direct quotations.

## **Findings**

We conducted semi-structured interviews with 10 South Asian women and 11 healthcare providers who deliver lifestyle counseling to South Asian women during pregnancy (Tables 1 and 2). Four women participated in face-to-face individual interviews and 6 participated in a single face-to-face focus group. Five healthcare providers (two medical doctors, three registered dietitians), participated in individual phone interviews and six healthcare providers (one physician's assistant, four registered dietitians, and one nurse) participated in a single face-to-face focus group. The average age of the mothers in our study was 34.5 (SD 5.8) years. Most women (88.9%) were born outside of Canada (Pakistan and India, 66.6%), and all women's parents were born in India, Pakistan, or Sri Lanka. All women spoke English, but two-thirds listed either Punjabi or Urdu as the primary language spoken at home. The women were highly-educated (56% were

university graduates) and likely to be married (78%). Most women had only one child (56%), and it had been 3.2 (SD 1.4) years since their last pregnancy. Only 2 of 9 women (22%) had a history of GDM, and two (22%) had a family history of type 2 diabetes in a first-degree relative. The average weight gain in the most recent pregnancy was 36.3 (SD 15.0) pounds.

Most of the healthcare providers interviewed were registered dietitians (55%), but we also interviewed medical doctors (18%), a certified diabetes educator (9%), physician assistant (9%), and a registered nurse (9%). These providers had been in practice for 6.8 (SD 5.4) years. Providers estimated that 75% of their clients or patients were of South Asian ancestry. Overall, 64% of providers saw patients aged 18-25, 82% saw patients aged 26-30, 100% saw clients aged 31-35, and 64% saw patients aged 40 or older; about 1 in 4 patients were pregnant (27%). All providers typically discussed both diet and physical activity during counseling visits.

Themes that emerged from the perspectives of South Asian pregnant women included: 1) locus of control; and 2) support from family, friends, and healthcare providers, while the themes identified among healthcare providers included: 1) cultural awareness; and 2) clinic management and resources. An overall theme between both South Asian pregnant women and their healthcare providers was the importance of the provider being culturally aware when providing clinical care and counseling to South Asian women. The themes are described below, with additional quotes to support each theme being provided in Table 3.

### ***Theme One: Locus of Control***

Our analysis suggests that an individual's locus of control is like a scale that operates with push-pull dynamics between one's intrinsic motivations and personal characteristics (e.g., self-efficacy, confidence, conviction) to other responsibilities/obligations and priorities. Other

responsibilities and commitments can act as barriers to healthful eating and physical activity. The operationalization of an individual's locus of control over perceived barriers differs depending on the individual. For example, some pregnant women with a high locus of control may overcome built environment-related barriers to attend scheduled or unscheduled programs at an exercise facility. Other women may only attend if it is within walking distance to their homes. Women may also have low levels of energy, which could stem from a low locus of control due to other commitments with work and family: *"Besides my energy level, there are only so many hours in the day. I was working full time. You come back home and you have dinner and that's it. That was the most I could do. If you asked me to do anything more, there would have been barriers—like time, my energy"* (Anika, Mother, Individual Interview). In addition to external environmental factors, women's internal motivations could be a factor in their locus of control, which in turn, influenced the decisions that they made regarding diet and physical activity. For example, some women indicated that they gave themselves permission to reward themselves with food: *"Splurge once in a blue moon, but don't go crazy. Like you've been hiding in a cave-kind-of-thing. Because some people eat like that"* (Priya, Mother, Individual Interview). In general, a woman's locus of control influenced her perceptions of whether she could overcome barriers and challenges to engage in physical activity and/or modify her diet.

### ***Theme Two: Support from Family, Friends, and Healthcare Providers***

In addition to this individualized prioritization, participants identified three partner groups who were involved in providing support related to dietary changes and physical activity: friends, family, and healthcare providers. This support came in the form of information exchange and encouragement. In relation to friends and family, many participants shared that their ability to

engage in physical activity or dietary practices was dependent on the amount of family support they received (e.g., flexibility to drop off an older child with her mother or mother-in-law in order to attend to physical activity, having a spouse to provide company and encouragement).

South Asian women engaged with family (e.g., mother, mother-in-law) and friends (e.g., other pregnant women or those with young children) to share and exchange nutrition and physical activity knowledge during the perinatal period. For example, many women mentioned that they received advice from close friends and family about optimal behaviours during pregnancy. Some of this advice included types of physical activities to avoid (e.g., avoid coming down the stairs too quickly, not to begin new regimens during pregnancy) or encouragement to continue moving and staying active. This guidance was not always viewed as prescriptive, but instead as well-intentioned suggestions. However, in cases where physical activity recommendations were related to an increased risk for miscarriage, it was surely followed. Furthermore, when women did not have access to a wide kinship network near them during their first pregnancy (e.g., if they were newer immigrants to Canada and most of their family members were living in their native countries), they felt as though they “*would have no idea about what would happen next*” (Rina, Mother, Focus Group). Some women further reiterated that they received more guidance around behaviours to avoid rather than what behaviours were optimal and would have appreciated receiving the latter. Much of the advice received from family members such as elders, grandmothers, and sisters were passed down generationally (e.g., stressing the importance of walking during pregnancy).

Furthermore, women spoke with their healthcare providers, who they considered to be trusted experts, to seek further information about prenatal health. Many expressed that they trust the information that comes from healthcare offices, although they would prefer if the information

were provided to them sooner (i.e., before their first visit with the obstetrician). Many women also mentioned that it would have been best if diet and physical activity advice came proactively from healthcare providers during the first trimester. For example, one participant said, *“I think as soon as a lady gets pregnant and they go to the doctor for the first time, all that information [about diet and hysical activity] should be provided. That, here’s what you can do, here’s where you can go. So that she at least has everything”* (Isha, Mother, Individual Interview). Another participant mentioned, *“it should be even like flyer or paper or if you have a computer, they can tell you some website on that paper that you can go there. It’s like whatever that person is comfortable with. So at least you should be aware of what you can do. And where is the help available”* (Dhakshini, Mother, Focus Group). Furthermore, another participant said, *“Even from school, [kids] bring, like Canada food guide. Like, you know, that type of thing. So I try to follow that. If you are pregnant, and you go [to the family doctor], and the doctor just gives you a chart, just a handy thing. More easy. At least somebody is going to read it. For pregnant women they should be available. When they go to see their doctor. Like a package, like we told before.”* (Ruthie, Mother, Individual Interview).

Women also considered their family doctors to be important contributors to knowledge exchange during the postnatal period, furthermore expressing a need for receiving information and resources. For example, one participant said, *“After 6 months, I went to the doctor every month. Blood work. To make sure everything was okay. I don’t want to downhill. She does give me nutritional facts. She checks my blood. Because I had gestational diabetes right. Towards the end. Like late. So that’s really important because you want to make sure that you’re really healthy, a healthy weight. And if you want to want to have another, you have to make sure you’re very*

*healthy. So having that doctor's support is important? Yes. I would want more resources from her"*  
(Rubina, Mother, Individual Interview).

### ***Theme Three: Understanding the Patient Population***

Healthcare providers described that knowing the patient population is very important to making optimal decisions around how and when to share lifestyle modification advice (adapting their advice to the specific needs of a patient). They empathized with the challenges that pregnant women experienced when making lifestyle modifications, their concerns for women's postnatal and downstream health outcomes, and issues related to compliance. Healthcare providers described how knowing the patient population solidifies through the years of clinical experience working with South Asian patients. This included understanding cultural nuances, foods, and cooking/eating practices. Healthcare providers who were not as familiar with South Asian foods but still practiced a very individualized approach to guide patients with dietary practices, used pictures and searched for additional information to get a better idea about what foods were being consumed. In addition, one healthcare provider who had many years of experience working with South Asian patients during pregnancy mentioned that she finds it challenging to advise patients when they do not feel comfortable disclosing sensitive information to her. In these cases, she still continues to try her best to learn more about her patient's unique circumstance, cultural influences, and perspectives through connecting with other practitioners on the care team. Having a diverse team of professionals caring for a single patient can further support the efforts made to better understand the patient population.

Despite how keen healthcare providers are in terms of getting to know their patients, they may still experience challenges related to language/translation, having access to accurate visuals

(i.e., illustrations of South Asian foods/meals), and tailored resources for this population. These barriers were consolidated through a reflection of whether patients were understanding current counselling approaches with clarity (e.g., recognizing whether language translation services are needed during the counselling session). For example, one healthcare provider said, *“I think language barriers can be a big barrier. You just hope that family members are conveying the information accurately. Sometimes I find that the husband will say something to the wife and then they start talking and I’ll have no idea what they are talking about or if they agree with the information, or if they have a question about the information. Sometimes that can be a little challenging. And like I said, some foods that I’m not familiar with, hopefully together we can figure out what it is and I can look it up in more detail. Sometimes not knowing all the specific foods can be a bit of a challenge”* (Lara, Registered Dietician, Individual Interview). Additionally, another healthcare provider also mentioned the challenges experienced when women hear stories that are in conflict with evidence-based health information—and there is limited time during the clinic visit to adequately address such inaccuracies. For example, *“I had a patient who had a miscarriage the other day, saying is it because I went up the stairs. Am I never supposed to go up the stairs, like how is that going to work. It has nothing to do with it. So they hear things, and I feel that’s more of a barrier. I only get like at maximum 20 mins with a patient, and they spend the other 23 hours and 40 mins with their families, husbands and all these other people who are telling them different things like you should eat a lot of fat and oils so baby can be healthy. You should be resting. That is another barrier, it’s time and only see them once a month. In their early pregnancy is when they are gaining the most weight, and making those decisions about their lifestyles”* (Patrice, Registered Dietician, Individual Interview). This perspective emphasizes the potential for including other family members (e.g., husbands, mothers, in-laws, elders) in patient-care models to be able to

better understand the patient population and thus tailor relevant and useful advice or guidance related to healthy active living during pregnancy.

#### ***Theme Four: Clinic Management and Tailoring of Resources***

Clinic set-up, processes, and access to patient education materials is an important component in the delivery of diet and physical activity counselling. Although healthcare providers recognized the importance of understanding the patient population, they cited a lack of accurate and up-to-date print and electronic resources for prenatal nutrition and physical activity tailored for South Asian families as being a barrier to optimal care. Although many healthcare providers expressed that having access to evidence-based, simple, and user-friendly patient-facing tools would improve the quality of care they are able to provide, they also recognized that it takes time to gain the experiences necessary to build a packet of relevant and applicable resources. For example, only one healthcare provider mentioned that she was able to develop her own resources to give to patients.

Some healthcare teams functioned as a family-health unit or had multidisciplinary providers (e.g., nurses, physician assistants), which allowed responsibilities to be distributed and roles to be maximized, being an advantage for patients and providers. For example, it was mentioned that a multidisciplinary team can help complement various sides of patient care in relation to diet and physical activity counselling and care delivery. For example, one care provider said, *“as a dietitian, we’re not really trained in physical activity prescription. It would be nice if we were. I think it would be helpful to have a kinesiologist on the team. It’s their area of expertise and it really complements what we do”* (Blanche, Registered Dietician, Individual Interview). Healthcare providers discussed the primary strategies they use to counsel women on nutrition and



physical activity. Nutrition care focused on portion control, monitoring blood sugars and glucose levels, eliminating/incorporating specific foods, meal balance, and aiming to be as specific as possible with the shared advice. The main physical activity advice was specific to building in post-meal walking. Healthcare providers also felt that women were more “compliant” and willing to modify their practices if they were receiving evidence-based advice and examples. For example, there was a need for resources that reflected South Asian foods (e.g., types of dishes, strategies for portion control). This is more important for care providers who were not South Asian themselves or those who did not have extensive exposure to South Asian foods. For those who did use external resources to supplement their education deliverables, they recognized budgetary and time-related restrictions and limitations to creating optimal materials.

#### ***Theme Five: Cultural Landscape***

For both pregnant South Asian women and their healthcare providers, the factors that influence their perceptions of lifestyle modifications are influenced by an encompassing cultural landscape. The cultural landscape of the South Asian community cannot be ignored if one is to understand collective and individual expressions and practices. Many participants referenced traditional (cultural) foods and cultural perceptions of physical activity with regards to their nutrition and physical activity choices. Within South Asian communities, elder family members will advise on specific prescriptions related to nutrition and physical activity recommendations. For example, one participant stated that her choice of physical activity is influenced to a degree by cultural knowledge. Many mothers identified that family was a source of support in providing information in addition to healthcare providers. Therefore, there was a passing down of knowledge between generations, including family members such as elders, grandmothers, and sisters.

The South Asian culture also influenced the type of cuisines that could be prepared. One participant spoke about the difficulties in preparing healthy food, but recognized the importance of maintaining a healthy diet especially during pregnancy: *“I try to cut rice out, but it’s impossible in our culture. So, I try to eat—like pitas, everything whole wheat. Everything brown. I try to make it less sugary, fatty. Before [during pregnancy] it was like anything and everything”* (Leena, Mother, Focus Group). There are also cultural expectations at food gatherings, where traditional food is prepared with specific recipes and ingredients. Pregnant South Asian women also fulfill the responsibilities in their role as a mother and wife, in which they are preparing meals for their family at dinner and for guests at social gatherings. Women may find it challenging to prepare healthy meals that accommodate the food preferences from their families and community.

Healthcare providers might also be influenced by the cultural landscape in how they provide information about nutrition and exercise that is culturally relevant to pregnant South Asian women. Healthcare providers recognize that South Asian cuisine may include foods that do not prioritize health and so there may be alternative ways to incorporate healthy eating into daily life: *“Especially when meals in the South Asian population are already carb heavy. Having more whole grains. Watching the fats. Choosing lower glycemic index foods. Staying away from all the sugary desserts and sweets”* (Bina, Registered Dietician, Individual Interview). When providing care to South Asian women, healthcare providers also recognize that they need to tailor their dietary advice based on the knowledge that they have about the culture. For example, a healthcare provider described how they would offer a balance between incorporating dietary changes while maintaining the cultural aspects in meals: *“I’ll say it in the beginning and sort of say “So you know our culture is a little different, some things we believe, I don’t want you to let go of your beliefs but we can sort of tailor it so we can kind of incorporate this ””* (Keela, Registered Dietician,

Individual Interview). Other healthcare providers would provide specific recommendations in making changes based on the diet described by women: *“So just looking at foods at their eating and trying to make very specific recommendations for that person. So an example might be, you are having white rice, so can we try [to] change that to a long grain boiled rice or could it be brown basmati rice. Could we try switching to that, [it’s] more so food based. When you do that in that way, the concept is not too hard”* (Jayma, Registered Dietician, Individual Interview). Healthcare providers also encourage women to incorporate physical activity with suggestions, such as walking after each meal. Therefore, healthcare providers needed to provide individualized and tailored advice about nutrition and physical activity based on the overarching cultural context of their patients.

As both healthcare providers and South Asian women are interacting within a cultural and clinical context where past and present experiences are fueling their interactions, there will naturally be a desire to hybridize traditional and Western lifestyle approaches. Hybridization may occur on a spectrum and be a different process for each individual, however, all pregnant women, both new immigrants and those who have already been living in Canada for several years, will likely face these contentions. This experience of hybridization makes it even more important to understand the patient’s needs, values, and perspectives, so that counseling can be tailored appropriately.

In summary, various components that influence individual care, expressions, patterns, and practices (the woman’s locus of control) exist within the context of a South Asian cultural landscape. Healthcare providers can also influence an individual’s care, expressions, patterns, and practices during pregnancy through the provision of prenatal care to women. As healthcare providers are trusted sources of guidance and information for pregnant women, a more holistic

awareness of cultural practices and a greater confidence in how to tailor their advice for South Asian families is essential to optimize care. Although tailoring resources for a specific cultural community may come with unique challenges (e.g., time constraints, lack of available resources), it is a relevant and important step to provide care that is rooted within a cultural context.

## **Discussion**

The intersection of the needs and wants of pregnant women and healthcare providers provide ample opportunities for the development of effective and meaningful recommendations for clinical practice change and the design of new lifestyle interventions. For example, consulting diverse perspectives can direct the creation of a culturally-tailored and evidence-based diet and physical activity intervention to achieve normal levels of blood glucose during pregnancy. A culturally-tailored approach can provide program planners and researchers deeper insight into end-user preferences for content, format, and preferred delivery method; and also help understand and overcome misconceptions related to the relationships between 1) miscarriages and physical activity and 2) food choices and blood glucose impacts.

Although many barriers and facilitators to healthy active living faced by South Asian women mirror those faced by women of other ethnicities (33), the intersectionality of the cultural landscape introduces unique opportunities to have a dialogue between healthcare providers and South Asian families. Some similarities include logistical issues such as time, family responsibilities, balancing the multiple roles filled by women in today's society, interest in doing what is best for the baby, and fear of miscarriages (34). Factors that are possibly unique to the South Asian community include the cultural advice and guidance from family/friend sources, especially from mothers, mothers-in-law, and grandmothers (e.g., 35).

To provide more culturally-aware care, healthcare providers should consider the following elements when developing or delivering prenatal care programs to South Asian women: a) focused and tailored knowledge around diet and physical activity modification (based on what is already being done or achieved), b) inclusion of and appreciation for the role of cultural foods, c) inquiring about patient experiences around how, when, and why specific foods are consumed or specific physical exercises are avoided, d) seasonal barriers to physical activity, access to family supports, personal factors/motivators, and e) resolving cultural misconceptions using a family-based approach (e.g., involving mothers, mothers-in-law, grandmothers). Healthcare providers expressed a need for more evidence-based information about healthy eating but struggle with lack of time and/or human resources (e.g., family medicine clinics not having access to a registered dietitian on-site), public health or informatics-related programming, which are all elements that could be addressed in the implementation of an intervention. In the meantime, healthcare providers and allied health providers could aim to learn more about their patients' perspectives so that they can better understand their values and beliefs, and safely tailor their counseling to optimally suit their patients' needs. To support healthcare providers, we have developed a guiding list of open-ended questions that can be used to initiate a dialogue about the cultural landscape that envelopes many patients' daily lives (Table 4). These questions were developed to reflect the interpretive nuggets of this study. Furthermore, we can turn to narrative-based medicine to position these recommendations within a context that can further benefit clinical practice. Narrative-based medicine is the application of narrative strategies to the practice of medicine. Similar to patient-oriented care which also places patients at the centre of their own care, narrative-based medicine can help healthcare providers harness the power of patient stories to better understand the factors that influence them on various levels (e.g., individual, family, cultural contexts). These suggested

questions can be used by healthcare providers who counsel South Asian women on healthy active living during pregnancy to elicit stories, learn from one another in an open environment, share conversations, and promote trust within care delivery.

In summary, pregnant women should actively seek out guidance around cultural foods, hybridizing cultural and western knowledge, and knowledge about safe exercises during the prenatal period, while healthcare providers want more evidence-based knowledge related to healthy active living during pregnancy. To merge these perspectives, interventions should include family-focused programs that incorporate new knowledge and support behavioural change (i.e., tailored lifestyle modification).

### Strengths and Limitations

The strengths of our study include the combination of individual interviews and focus groups with the inclusion of two different participant groups to garner diverse perspectives. Furthermore, the women we interviewed were diverse (e.g., in terms of immigrant status, first generation vs. second generation, first language) and representative of the South Asian population living in the Peel region. We also interviewed diverse healthcare providers who counsel pregnant women (e.g., physicians, dietitians, physician's assistants, nurses) to capture a wide array of perspectives, ideas, and insights. We also used multiple strategies to ensure trustworthiness: a) prolonged engagement in the field to interview different participants; b) investigator triangulation to incorporate diverse experiences of our multidisciplinary research team and to interpret the data; c) thick descriptions of the context setting and participants' experiences, and; d) an audit trail to document the process used within this study (36). Despite these strengths, we understand that some limitations of our study may include the missing perspectives of a) kinesiologists and exercise

physiologists who may counsel pregnant women on physical activity and b) obstetricians, who may also counsel pregnant women on dietary change and physical activity. We found that the clinics from which we recruited (i.e. those which saw a high number of South Asian pregnant women) did not have a dedicated professional to discuss physical activity (e.g. kinesiologist). This is a limitation of this work, but also reflects the “real-world” setting. The reason we did not include obstetricians is because we wanted to focus our understanding on early-pregnancy information exchange. We asked both women participants and healthcare providers about physical activity preferences/barriers/facilitators. In addition, although the majority of the South Asian women included in this study have completed a higher level of education (graduate or professional licensure), it should be noted that 1) we did not stratify or recruit based on educational status; 2) our recruitment strategy was purposeful. For example, after reviewing the first few transcripts, we found that we had recruited mostly first-time pregnant second-generation immigrants, so we adjusted our sampling process to recruit first-generation female immigrants with at least one child. We did not use maximum variation sampling related to education status. Finally, although we understand the benefits of focus groups (e.g., participants can build on each other’s ideas, we can observe statements where participants agree or disagree), we also recognize that group settings may alter people’s desire to share personal information about themselves, which can constrain integrity. In order to minimize this, we created a safe and secure environment by building trust with the interviewees, reiterating the important role of the research team in upholding participant confidentiality, allowing participants to freely choose between focus groups and individual interviews, and building a culture of on-going consent where participants can opt-out at any point during the study.

## **Conclusion**

Pregnant South Asian women have a two-fold increased risk for developing GDM compared to their white Caucasian counterparts. Considering the complex cultural and contextual factors associated with lifestyle changes, we used an interpretive description approach to better understand the South Asian community's beliefs towards diet and physical activity during pregnancy and suggest recommendations for clinical practice change. In regards to the barriers and facilitators to lifestyle change during pregnancy, the themes that emerged from the perspectives of South Asian women included: 1) locus of control; and 2) support from family, friends, and healthcare providers; while those identified among the 11 healthcare providers included: 1) understanding the patient population; and 2) clinic management and resources. The cultural landscape was an important theme that was common to both South Asian pregnant women and healthcare providers in regard to a milieu housing both barriers and facilitators. A better understanding of these cultural underpinnings can be used to better inform clinical practice change and the development of successful interventions tailored for pregnant South Asian women or their healthcare providers. Future directions should consider the cultural landscape and women's preferences around knowledge exchange when proposing programs that encourage lifestyle change.



<i>Characteristic</i>	<i>Value</i>	
	Mean (Standard Deviation)	Range
Age (yrs)	34.5 (5.8)	28.7 to 41.9
Years lived in Canada	12.5 (6.8)	5.0 to 25.0
Time since last pregnancy (yrs)	3.2 (1.4)	0.5 to 5.0
Time since GDM (yrs)	1.8 (1.8)	0.5 to 3.0
Pregnancy weight gain (lbs)	36.3 (15.0)	12.5 to 52.5
	Count (Percentage)	
Born in Canada		
Yes	1 (11.1%)	
No	8 (88.9%)	
Place of birth		
Pakistan	3 (33.3%)	
India	3 (33.3%)	
Sri Lanka	1 (11.1%)	
Germany	1 (11.1%)	
Canada	1 (11.1%)	
Mother's country of birth		
India	4 (44.4%)	
Pakistan	3 (33.3%)	
Sri Lanka	2 (22.2%)	
Father's country of birth		
India	5 (55.6%)	
Pakistan	2 (22.2%)	
Sri Lanka	2 (22.2%)	
Primary language spoken at home		
English	3 (33.3%)	
Punjabi	3 (33.3%)	
Urdu	3 (33.3%)	
Highest level of education completed		
Less than high school	1 (11.1%)	
High school diploma/certificate	1 (11.1%)	
College or college equivalent	1 (11.1%)	
University bachelor's or equivalent	1 (11.1%)	
Graduate or professional licensure (e.g. MD)	5 (55.6%)	
Employment Status		
Employed full-time	5 (55.6%)	
Employed part-time	2 (22.2%)	
Unemployed	2 (22.2%)	
Current maternity leave	2 (22.2%)	
Marital status		
Married/common-law	7 (77.8%)	
Divorced/separated	2 (22.2%)	
Currently pregnant	1 (11.1%)	
Number of children		

0	0 (0.0%)
1	5 (55.6%)
2	1 (11.1%)
3	2 (22.2%)
4	1 (11.1%)
Has had GDM in the past	2 (22.2%)
Family history of GDM in first-degree relative	2 (22.2%)

\*One participant refused to provide these parameters.

Table 1. Characteristics of participating mothers (n=9\*)

<i>Characteristic</i>	<i>Value</i>	
	<i>Mean (Standard Deviation)</i>	<i>Range</i>
Years of experience	6.8 (5.4)	1.6 to 20.0
% of clients who are pregnant women	26.9% (12.2)	10.0 to 45.0
% of clients who are SA women	74.9% (29.7)	20.0 to 100.0
	<i>Count (Percentage)</i>	
Profession		
Registered dietitian	6 (54.5%)	
Medical doctor	2 (18.2%)	
Certified diabetes educator	1 (9.1%)	
Physician assistant	1 (9.1%)	
Registered nurse	1 (9.1%)	
Age range of patients seen		
18-25	7 (63.6%)	
26-30	9 (81.8%)	
31-35	11 (100.0%)	
40+	7 (63.6%)	
Topics discussed		
Diet only	1 (9.1%)	
PA only	0 (0.0%)	
Diet + PA	11 (100.0%)	
None (other)	0 (0.0%)	

Table 2. Characteristics of participating healthcare providers. (n=11)

Key Themes	Supporting Quotes
<b>Perspectives of South Asian Pregnant Women</b>	
<b>Theme 1: Locus of Control</b>	<p><i>“besides my energy level, there are only so many hours in the day. I was working full time. You come back home and you have dinner and that’s it. That was the most I could do. If you asked me to do anything more, there would have been barriers—like time, my energy”</i> (Anika, Mother, Individual Interview).</p> <p><i>“Splurge once in a blue moon, but don’t go crazy. Like you’ve been hiding in a cave-kind-of-thing. Because some people eat like that.”</i> (Priya, Mother, Individual Interview).</p>
<b>Theme 2: Support from Family, Friends, and Healthcare Providers</b>	<p><i>“I feel like it was my husband who used to just kind of get me up and say ‘let’s go, we’re both going to go [for a walk]’. I felt like when he would push me to it, that was the only time I kinda wanted to get out and go”</i> (Jaya, Mother, Focus Group).</p> <p><i>“[South Asian pregnant women] trust and go to their family doctor. If [the family doctor] could recommend healthy workshops or health groups in the community, it would be better.”</i> (Asha, Mother, Individual Interview).</p>
<b>Perspectives of Healthcare Providers</b>	
<b>Theme 3: Understanding the Patient Population</b>	<p><i>“it’s years of experience and learning from the patients”</i> (Nina, Registered Nurse, Individual Interview)</p> <p><i>“if I feel like I’m not getting my point across then they have to rebook under a translator.”</i> (Disha, Registered Dietitian, Individual Interview).</p> <p><i>“I learned a lot when I did our patient and high risk class in Surrey. I did a clinic with one of the physicians, I learned a lot of stuff about diet and exercise of South Asian women from her.”</i> (Danihya, Registered Dietitian, Individual Interview).</p>

<b>Theme Four: Clinic Management and Tailoring of Resources</b>	<p><i>“it’s years of experience and learning from the patients. Because you learn a lot from them. So I have put together a nice neat portfolio or tool box I could say about information I can pull out and counsel them”</i></p> <p>(Dharsha, Registered Dietitian, Individual Interview).</p>
<b>Overall Theme Between both South Asian Pregnant Women and Their Healthcare Providers</b>	
<b>Theme Five: Cultural Landscape</b>	<p><i>“because culturally they don’t believe that you should exercise, but [do allow] exercises where you don’t have to do a lot of jumping around [as] to avoid miscarriages”</i></p> <p>(Durga, Mother, Focus Group).</p> <p><i>“more awareness among the community. Like the expectation at the gathering is not that is going to be a lot of food. I think there has to be a change in the overall expectation.”</i></p> <p>(Ani, Mother, Individual Interview).</p> <p><i>“so just looking at foods [they are] eating and trying to make very specific recommendations for that person. So [an] example might be, you are having white rice, so we can try [to] change that to a long grain boiled rice and could it be brown basmati rice.”</i></p> <p>(Dharpita, Registered Dietitian, Individual Interview).</p>

Table 3. Supporting Quotes for Key Themes

Open-ended Questions
<ol style="list-style-type: none"> <li>1) Who do you currently live with and how do you share the food preparation chores among your household?</li> <li>2) What kinds of foods do you eat on a regular basis?</li> <li>3) Do you receive advice from your family or friends about what types of exercise you should be doing/avoiding during pregnancy? What kinds of advice do you hear?</li> <li>4) Do you follow this advice? Why or why not?</li> <li>5) Do you receive advice from your family or friends about what types of food you should be eating/avoiding during pregnancy? What kinds of advice do you hear?</li> <li>6) Do you follow this advice? Why or why not?</li> </ol>

Table 4. Guiding list of open-ended questions to initiate a dialogue about the cultural landscape for healthcare providers

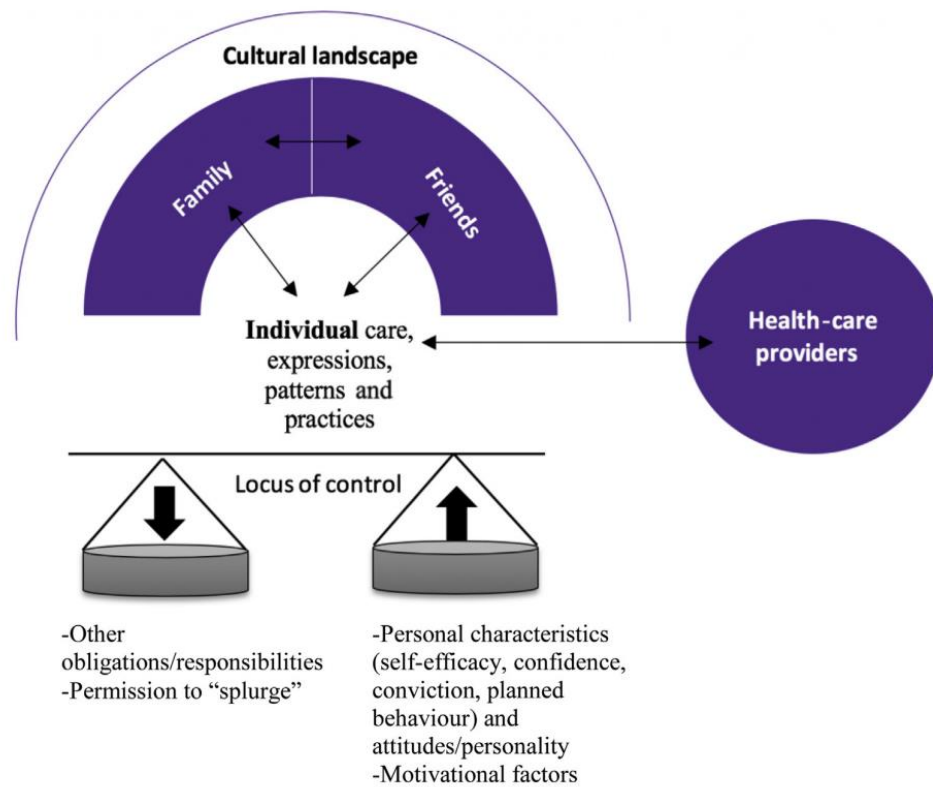


Figure 1. Schematic diagram summarizing how individual pregnant South Asian women's care, expressions, patterns, and practices are influenced by their locus of control, culture, family, friends, and their healthcare providers

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## Appendix 1: Interview guide

### Interview guide 1: South Asian Participants

#### Physical Activity Questions

1. Please consider the forms of physical activity you have been able to *do* in the past that were helpful and, at times, enjoyable. Can you describe this form or forms of physical activity?
  - a. When able to do this form or forms (of physical activity) please describe how often this was possible? How long were you able to do this activity per time?
2. If you had a convenient way of doing your most preferred modes of physical activity (as indicated above), describe how often you feel you could do them? Why?
  - a. If so, what about this plan ‘works effectively’ for you?
  - b. What about this plan do you think would be most challenging?
    - i. If you do **not** think you could follow this activity plan, why not?
3. What changes would you make to the plan to better fit your lifestyle and available time? Please describe these changes.
4. What challenges do you anticipate confronting in being able to reach your exercise goal?
  - a. Please describe what resources you think you would need to overcome these barriers?
    - i. E.g., Step-counters? Exercise Monitors? Online resources? Apps? Workout buddy? Etc.,

#### Nutrition Questions

1. Please consider forms of healthy eating that you have been able to do in the past, that were helpful (even temporarily) and, at times, enjoyable. Can you describe these forms of healthy eating? What types of foods were you eating? Can you provide some examples? What foods were you emphasizing? What foods were you eliminating?
  - a. When you were able to do this form or forms of healthy eating, can you describe how consistently you were able to work towards your personal goals? Why? What got in the way of this? What helped you succeed?
2. Do you think you could follow a healthy eating plan to reach the goals you have identified? What would this plan look like for you?
  - a. What foods would you want in your plan?
  - b. What foods would you not like to have in your healthy eating plan?
  - c. If not able, why do you think you could not follow a healthy eating plan?

3. What changes would you make to the plan to help it fit your lifestyle and time available? (E.g., Meal prep? Buying in bulk? Changes to shopping schedule? Using a different grocery store?)
  - a. What challenges do you see in being able to follow these and other healthy eating suggestions?
  - b. What resources do you think you will need to overcome these barriers? (E.g., New recipes? Apps?)
4. Considering both healthy physical activity and eating, would you be more willing to change either your physical activity or eating habits to achieve your health goals?
  - a. If so, why would one be easier to change than the other? Why?
  - b. What challenges do you see in being able to change both eating and physical activity patterns?
  - c. What resources do you think you will need to overcome these barriers? Please describe these. When and why do you think these would be helpful?

### **Interview guide: Healthcare provider**

1. Please describe your clinic setting.
  - a. Who in your clinic counsels pregnant women about nutrition and physical activity? (e.g. MD, nurse, dietitian, etc.,) Why is it set up this way?
2. Do you feel sufficiently comfortable providing dietary advice to South Asian women during pregnancy?
  - a. Why do you feel that you are so comfortable doing so?
  - b. Why do not feel comfortable doing so?
  - c. Are there aspects of diet and exercise advice that you find particularly challenging to convey to South Asian women?
3. Do you feel sufficiently comfortable providing exercise/physical activity advice to South Asian women during pregnancy?
  - a. Why do you feel that you are comfortable doing so?
  - b. Why do you feel not comfortable doing so?
4. Which dietary patterns/guides and activity habits do you recommend (Canada's Food Guide, Mediterranean diet, DASH, etc.)? Why? How do you use these resources in your counselling? Please describe a mock situation.

5. Do you provide any specific advice about the potential role of diet and physical activity to prevent gestational diabetes?
  - a. If no, why not?
  - b. If yes, please describe the advice that you give.
6. What guidance and resource materials do provide pregnant women about nutrition and physical activity? Are these resource materials tailored for South Asian women? Please describe a mock situation.
7. In what ways do you adapt your advice on diet for South Asian women? Please describe a mock situation.
8. In what ways do you adapt your advice on exercise for South Asian women? Please describe a mock situation.
9. What barriers do you feel exist when delivering lifestyle advice to pregnant women?
10. In your opinion, what are the most important factors that help you determine whether a mother will be adherent to recommendations for changes in diet and/or exercise patterns? How do you determine this? How do you use this in your practice? Please describe a mock situation.
11. In your opinion, what could be done to improve a woman's adherence to diet or exercise?

**CHAPTER 3: IDENTIFYING “GEMS” AND “GAPS” IN PRENATAL SETTINGS:  
USING A SYSTEMATIC REVIEW AND NARRATIVE SYNTHESIS TO EXPLORE  
KNOWLEDGE TRANSLATION TOOLS DESIGNED FOR SOUTH ASIANS**



**Identifying “Gems” and “Gaps”:  
Using a Systematic Review and Narrative Synthesis to explore Knowledge Translation  
Tools Designed for South Asians in Prenatal care**

**Abstract**

South Asians encompass a diverse global community who experience unique socio-cultural climates around pregnancy and birth. Studying the components of KT tools targeting this population may allow for a better direction on future intervention design, development, and evaluation. This study is a systematic review and narrative synthesis of the published and grey literature on KT tools for the prenatal setting that are tailored for the South Asian population. Narrative synthesis is helpful to explore the effectiveness of interventions of diverse methodologies and focuses on the following key elements: 1) developing a theory of how the intervention works, why and for whom; 2) developing a preliminary synthesis of findings of included studies; 3) exploring relationships in the data; and 4) assessing the robustness of the synthesis. The search generated 1054 titles and abstracts after duplicates were removed. Post title/abstract screening and full text assessment, 11 studies were included in the final narrative synthesis. We report on the general and specific features that contributed to intervention acceptability. These include the general features of: 1) trusted tool delivery; 2) the packaging of empowering, motivating, and myth dispelling evidence-based health messages; 3) simple, structured, co-ordinated, and visually reinforced design that has been pilot-tested. Within these major categories, the specific features that are particularly nuanced for this population include: 1) increasing trusted delivery by using female voice artists (to emulate trusted and amicable female relatives); 2) integrating family-centric messaging; 3) adapt designs to local practices, cultural factors, and use familiar melodies to supplement audio-visual material. These elements can be

implemented to design better suited interventions for pregnant South Asian women and their family support systems across different geographies and contexts. It is vital that KT tools continue to be theory-informed and evidence-based and that corresponding implementation efforts for this priority population continue to be evaluated in various contexts, including high-income countries.

## **1.0 Introduction**

The development of new knowledge via health research does not automatically contribute to widespread implementation or improved health outcomes (CIHR, 2015). There is a need for coordinated and intentional efforts to close the research-practice gap by translating research evidence into practice—a process referred to as Knowledge Translation (KT). KT is the dynamic and iterative process of applying research to strengthen health services, products, and systems. An emerging sub-field of KT is the direction of KT toward patients and caregivers via tailored tools, resources, and products (Albrecht et al., 2017; MacDermid et al., 2013). KT tools are a sub-group of KT interventions that present complex research-based evidence in user-friendly, appealing formats to provide recommendations or meet knowledge needs. Essentially, KT tools aim to empower patients/caregivers with important information relevant from a preventative or therapeutic standpoint. Examples of KT tools include products that inform health decision-making such as patient-centered decision supports, infographics, brochures, and digital resources (videos, text messages).

Pregnancy, childbirth, and the postnatal period (sometimes collectively referred to as the 1000 days of pregnancy) are unique periods of life that are significantly influenced by physiological, social, and cultural experiences. Pregnancy-related knowledge is in high demand and knowledge related to healthy lifestyles, childbirth, infant care, and mothering skills are examples of gaps (Robinson et al., 2018). During this time, efforts made to connect pregnant women to evidence can improve health decision-making, maternal and child health outcomes, and reduce short and long-term healthcare costs. People of South Asian ancestry, the largest and fastest growing ethnic group in many high-income countries (e.g., Canada) (Statistics Canada, 2018), may express perceptions of pregnancy that differ from dominant cultures and mainstream healthcare (Ladha et al., 2010; Kandasamy et al., 2020). We know that knowledge gaps and time/logistical

challenges exist (Kandasamy et al., 2020)—barriers that can potentially be addressed by scalable KT tools. Thus, better understanding effective KT tools for South Asian women is an important step to proposing future recommendations for KT tool development and implementation.

This study is a systematic review and narrative synthesis of the published and grey literature on KT tools for the prenatal setting that are tailored for the South Asian population. We sought to understand the breadth and depth of KT tools that have been developed and evaluated (including their intended purpose), how they are being evaluated, and whether they are demonstrating hypothesized effects.

## **2.0 Methods**

### *Study Design*

This is a systematic review and narrative synthesis (Popay et al., 2006). In this case, paring these two approaches is important to ensure that we search the literature broadly and replicability but with the intention of exploring the specifics of the interventions. In particular, narrative synthesis is helpful to explore the effectiveness of interventions of diverse methodologies and focuses on the following key elements: 1) developing a preliminary synthesis of findings of included studies; 2) developing a theory of how the intervention works, why and for whom; 3) exploring relationships in the data; and 4) assessing the robustness of the synthesis (Popay et al., 2006).

### *Search Strategy*

In consultation with an information specialist, we developed a comprehensive search strategy for the MEDLINE, CINAHL, and EMCARE databases to identify English-language studies that evaluated KT interventions specifically designed to influence South Asian women's knowledge, perceptions, and/or health-based practices during pregnancy. South Asian refers to

those who have ancestry in the Indian subcontinent (India, Pakistan, Bangladesh, Nepal, Sri Lanka) and was reflected in the search strategy. Search terms were focused on knowledge translation, pregnancy, South Asian populations, and evaluations of knowledge/attitude/practice change (Full search strategies for all three databases can be found in Appendix 1). The initial search was conducted in May 2020 and updated until September 2020. The search captured qualitative, quantitative, and mixed methods articles published over the last decade (between 2010 and 2020). The database search was supplemented with a grey literature search as per guidance from the Canadian Agency for Drugs and Technologies in Health (CADTH) Grey Matters Checklist (Grey Matters, 2018).

All English-language research articles that evaluated a KT intervention tailored for pregnant South Asians and assessed outcomes related to knowledge, attitude, and/or practice change using a defined control were included. Studies that were not published as full primary research reports, such as conference abstracts, theses, and letters to the editor were excluded. The lead author (SK) screened all titles and abstracts of the studies identified in the electronic search to arrive at a list of articles for full-text review. The initial screening completed by SK was verified by a second graduate student reviewer (AB). Discrepancies were discussed until agreement was achieved. Four graduate student reviewers worked in pairs to independently and in duplicate assess the eligibility of each full text article using an a priori inclusion form (SK, AB, JL, UM). After a series of calibration exercises, data was extracted using a predefined data extraction worksheet. Both of these tasks were conducted independently and in duplicate by pairs of reviewers. The data extraction form was developed through a collaborative effort amongst the research team and included the following main criteria: title, author, year of publication, country, study objectives, methodology, description of included participants, description of the KT tool, description of the

control, description of the primary and secondary outcomes, follow-up period, successful components of the intervention, and future directions of the research. Disagreements associated with data extraction were resolved by discussion until consensus was reached.

Methodological quality assessment: For randomized controlled trials (RCTs), methodological quality was assessed by one reviewer (SK) using the Cochrane Risk of Bias Tool (Higgins et al., 2011). This tool has been deemed the most comprehensive for assessing potential for bias in RCTs and has become the standard approach for systematic reviews (Higgins et al., 2011; Jorgensen et al., 2016). An overall quality rating of low, high or unclear risk of bias is assigned to each RCT based on the following components: random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective reporting, ‘other’ sources of bias. For all other quantitative study designs, methodological quality was assessed by one reviewer (SK) using the Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project). Validity (content and construct) and inter-rater reliability have been established for this tool (Thomas et al., 2004). A global quality rating of weak, moderate or strong is assigned to each study based on the following components: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity, and analysis.

Data analysis: Using direction from Hong et al., 2017, a data-based convergent synthesis design was used. All included studies were analyzed using the same synthesis method after data transformation (quantitative data transformed into themes). A narrative analysis describing the extracted variables was conducted to summarize the findings (Popay et al., 2006). The goal of a narrative synthesis is to summarize and explain the findings of included studies by using a textual

approach to develop a theory of how the intervention works, why, and for what kind of target audience; develop a preliminary synthesis; investigate connections within and between studies; and assess the robustness of the synthesis (Popay et al., 2006). We assessed outcomes based upon a classification system for assessing patient-focused interventions, with distinctions being made to describe positive effects, mixed effects, no effects, and unclear (Coulter et al., 2006). The outcomes assessed included patient knowledge, patient experiences, service utilization/costs, and health practices/status and were reported via textual descriptions. Finally, we applied the WIDER Recommendations Checklist to describe the reporting quality of the KT tools (Albrecht et al., 2013).

### **3.0 Findings**

The search generated 1054 titles and abstracts after duplicates were removed. After title/abstract screening, 48 full text articles remained and were assessed for eligibility. Following full text screening step, 37 articles were excluded, leaving 11 in the final narrative synthesis (Figure 1.0).

The 11 included studies were spread across the following countries: India (n=9), Nepal (n=1), and Bangladesh (n=1) and research methodologies: randomized control trials (n=1); pre/post studies (n=3), quasi-experimental studies (n=3), and other designs with a clearly defined control group (n=4) (See Appendix A for details on included studies).

Risk of bias and WIDER Recommendations Checklist: All studies were assessed at high risk of bias (RCTs) or weak methodological quality (non-RCT quantitative studies). The main reasons were due to 1) lack of blinding and minimization against contamination; and 2) due to blinding and data analyses, respectively (Appendix C). Gaps in KT tool reporting as gleaned from

the WIDER Recommendations Checklist consisted of overall limitations in reporting intervention intensity, adherence/fidelity, change techniques, and the causal processes targeted by change techniques (Appendix D). As a result, it is important to note that the gravity of findings should be considered through this lens.

Studies used the following modes to bundle and deliver antenatal health messages: digital-based tools, either mobile or video (John et al., 2015; Chowdhury et al., 2019; Murthy et al., 2019; Ilozumba et al., 2018a; Ilozumba et al., 2018b), paper-based tools (Ayekpam et al., 2011; Josan et al., 2015; Khan et al., 2013; Parashar et al., 2013; Shivalli et al., 2015; Sharma et al., 2018), and melody-based tools (Sharma et al., 2018). Nine studies utilized patient-facing tools (Ayekpam et al., 2011; Chowdhury et al., 2019; John et al., 2015; Josan et al., 2015; Khan et al., 2013; Murthy et al., 2019; Parashar et al., 2013; Shivalli et al., 2015; Sharma et al., 2018) and two studies used healthcare worker-facing tools (Ilozumba et al., 2018a; Ilozumba et al., 2018b).

The majority of tools were developed to address safe pregnancy, birth, and/or neonatal care (Ayekpam et al., 2011; Chowdhury et al., 2019; Ilozumba et al., 2018a; Ilozumba et al., 2018b; John et al., 2015; Khan et al., 2013; Murthy et al., 2019; Parashar et al., 2013; Sharma et al., 2018; Shivalli et al., 2015). One study was developed to strengthen gestational diabetes education (Josan et al., 2015). Tools were designed using theory (Shivalli et al., 2015), formative research (Ayekpam et al., 2011; Ilozumba et al., 2018a; Ilozumba et al., 2018b; Murthy et al., 2019), and prioritization of community-based approaches (Khan et al., 2013; Parashar et al., 2012; Sharma et al., 2018). Three studies did not describe how the intervention was designed (Chowdhury et al., 2019; John et al., 2015; Josan et al., 2015).



Eight studies evaluated single component tools (Ayekpam et al., 2011; John et al., 2015; Josan et al., 2015; Ilozumba et al., 2018a; Ilozumba et al., 2018b; Chowdhury et al., 2019; Khan et al., 2013; Murthy et al., 2019) and three studies evaluated multiple component tools (Parashar et al., 2013; Shivalli et al., 2015; Sharma et al., 2018).

Five studies evaluated digital-based tools, either mobile or video (John et al., 2015; Chowdhury et al., 2019; Murthy et al., 2019; Ilozumba et al., 2018a; Ilozumba et al., 2018b). Three of these evaluated a patient-facing mobile tool for one-on-one information exchange (Chowdhury et al., 2019; Murthy et al., 2019; John et al., 2015). John et al., (2015) evaluated a video-based childbirth teaching tool (educational video tailored for pregnant women). This format was selected because videos can be used to visualize real and simulated problems, via help from motion and animation technologies (John et al., 2015). The goals of the video were to increase maternal knowledge regarding third trimester antenatal care, the labour process, postnatal care, newborn care, and anxiety reduction to promote safe deliveries. Chowdhury et al., (2019) evaluated *Aponjon*, a tool designed to disseminate generalized behavior change communication messages quickly and easily to women about the need for prenatal care, dispelling myths and misconceptions around pregnancy and the postpartum period, building awareness of pregnancy and newborn warning signs, newborn feeding practices, post-partum family planning, and nutritional intake to improve maternal health outcomes. Messages were tailored for two separate modules--one during pregnancy and another after delivery. Similarly, Murthy et al., (2019), evaluated the *mMitra* package, which consisted of 145 voice messages designed to share prenatal (from 6 weeks) and postpartum health information (to 1-year). Messages were delivered two times per week during pregnancy, one time per day during the first week postpartum, and then reduced to two messages per week from the second week of infancy to 1-year postpartum. *mMitra* also provided a free call-

back service during the first 48-hours after a message was sent in case women wanted to listen to the message again. The translations were tested for appropriateness, cultural nuances, and for tone. The final voice message, which was approximately 2 minutes long, began with a familiar ‘jingle’ to alert family members to pass the household phone to the pregnant woman or to put the call on speaker. The message ended with a reiteration of the key components. All messages were recorded in a female voice designed to represent an educated but amicable female relative (Murthy et al., 2019).

Two studies evaluated healthcare worker-facing mobile tools. Healthcare workers used the *Mobile for Mothers* (MFM) application during routine home educational visits with pregnant/lactating women in their communities (Ilozumba et al., 2018a; Ilozumba et al., 2018b). The *MFM* tool consisted of four modules: 1) registration of the pregnant woman; 2) antenatal care; 3) intra-natal care (e.g., delivery at a healthcare facility or with a skilled health professional); and 4) postnatal care. The mobile application also utilized multimedia functions with health information being presented to pregnant women through text, pictures, and voice prompts (Ilozumba et al., 2018a; Ilozumba et al., 2018b). Of the five studies that evaluated digital-based tools, four reported that the tool led to significant improvements in maternal health knowledge compared to their respective control groups; one study had mixed results (See Appendix B for a summary table on patient-focused outcome data).

Six studies evaluated paper-based tools (Ayekpam et al., 2011; Josan et al., 2015; Khan et al., 2013; Parashar et al., 2013; Shivalli et al., 2015; Sharma et al., 2018). Ayekpam et al., (2011) evaluated the effectiveness of an antenatal booklet summarizing key newborn danger signs and John et al., (2015) evaluated an in-hospital antenatal video-assisted teaching tool on childbirth education. Topics covered include antenatal care during the third trimester, labour processes,

postnatal care, newborn care, and spacing methods. Shivalli et al., (2015) evaluated tailored communication and home-based reminder materials (with appropriate messages and pictures) that were informed by data from a personalized assessment visit. Pregnant women were asked to select and try new recommended practices over a period of 12 weeks. Home-based reminder material were affixed in an appropriate place for visual reinforcement (Shivalli et al., 2015). Khan et al., (2013) evaluated a behaviour change communication package focused on changing the adverse behavior of pregnant women regarding neonatal care. Information was conveyed using pamphlets with simple health messages in the local languages (Hindi and Urdu). The package included information about institutional delivery, the principle of the clean birthing practices (“five cleans of birth”), danger signs, and key newborn handling practices (e.g., the importance of hand-washing). Similarly, Parashar et al., (2012) evaluated pictorial health messages under following headings: safe and clean delivery by trained personnel or safe and clean home delivery, use of disposable delivery kit, cord care, eye care, home-based thermal care and prevention of hypothermia in neonates, i.e., skin to skin contact method (kangaroo mother care), breastfeeding, prevention and management of breastfeeding-related problems, danger signals, and physiological variants of neonate. Tools of behavior change communication included one-on-one counseling, posters, pamphlets, and demonstration (Parashar et al., 2012). Josan et al., (2015) assessed the impact of a one-time structured, generalized in-hospital gestational diabetes (GDM) teaching program for antenatal mothers. Sharma et al., (2018) evaluated a combined paper-based and melody-based tool. The authors describe a co-created process where local groups were invited to compose song lyrics that incorporated key antenatal health messages to accompany popular melodies. The groups presented their songs and dances in a festival organized and judged by the community. The most captivating songs were performed in progression through the villages. After

the festival, a wall chart (*Holy Duty Wall Chart*) summarizing key health messages was distributed to each household (Sharma et al., 2018). Of the six studies that evaluated paper-based tools, three studies reported that the tool led to significant improvements in maternal health knowledge compared to their respective control groups; two had mixed results; and one did not assess change in knowledge (See Appendix B for a summary table on patient-focused outcome data).

**Strengths of KT Tools:** The key goals of tool design—1) simplifying and directing key evidence-based health messages to the audience of interest through a tailored approach that 2) supports the navigation toward the intended destination—are further amplified by general and specific characteristics that contribute to improved acceptability (Table 1).

**Analogy:** To highlight the general and specific characteristics of the KT interventions included this review, we have developed an analogy of a sailboat being steered to a specific destination. The sailboat symbolizes the vessel on which cargo is being transported. This vessel represents the KT tool (e.g., booklet, video, etc.) and the cargo represents the specific health messages to-be imparted (e.g., nutrition recommendations, knowledge about the importance of early screening, etc.). In line with sailing practices, the luff (the sail’s leading edge), wind, waves, and helmsperson (the person who steers the ship) work in tandem to ensure that the vessel is oriented in the correct direction and headed to the correct destination.

**1. Destination:** To whom is this information headed? What are the specific needs of the audience who is receiving the “sailboat” of information? What components of language or health literacy should be considered? What are effective approaches to make connections between knowledge and practices for this specific group?

**2. Cargo:** What is being carried on the “sailboat”? What kind of consignment is being delivered?

This component is essentially considering the type of health messages that are being packaged and delivered via the sailboat. It is noted that supportive information that motivates and empowers behaviour change (John et al., 2015; Josan et al., 2015; Shivalli et al., 2015) and dispels misconceptions and fears (John et al., 2015) are important aspects to consider when designing health messages. Furthermore, family-centric messaging has increased uptake for this population (Shivalli et al., 2015).

**3. Direction:** Is the intervention on course to reach the destination? How are barriers to reach being assessed and addressed? Who is steering this “sailboat”—is it an experienced and well trusted helmsperson)? It was noted that interventions delivered by a trusted (or recognizable) local community member was integral to acceptability (Ilozumba et al., 2018b; Khan et al., 2013; Murthy et al., 2019). Specific for this population, multi-media tools that use a female voice to emulate a trustworthy female family member may have higher uptake (Murthy et al., 2019).

**4. Craftmanship:** What engineering and construction considerations were made to contribute to the esthetics of the “sailboat”? What are the secondary components of the “sailboat” and are they designed to reinforce the “sailboat’s” buoyant properties? The use of simple language and explanations (Ayekpam et al., 2011), visuals that reinforce text-based messages (Ayekpam et al., 2011; Shivalli et al., 2015), accessible mobile technology (Chowdhury et al., 2015; Ilozumba et al., 2018a; Ilozumba et al., 2018b), structured design (Josan et al., 2015), trimester-timed messaging (Murthy et al., 2019), pilot-tested messages and tools (Murthy et al., 2019), and re-iterating of key messages (Murthy et al., 2019; Shivalli et al., 2015) are important elements of

craftsmanship. Within the context of South Asian health, adaptation to local practices (Murthy et al., 2019; Parashar et al., 2013; Sharma et al., 2018), the incorporation of cultural nuances (Murthy et al., 2019; Sharma et al., 2018), and use of familiar jingles/melodies (Sharma et al., 2018) have been especially worthy of enhancing acceptability among pregnant women.

There are general characteristics that may apply to many different contexts and populations, however, the presence of the “sailboat” in South Asian “waters” (culture) may direct specific changes to the buoyant properties or craftsmanship to make it more appealing and thus increase uptake.

## **5.0 Discussion**

This systematic review and narrative synthesis reports 11 control-group evaluations of KT tools aiming to improve the knowledge, attitudes, and/or health practices of pregnant South Asians. All reported studies were conducted in South Asian countries and focused on general antenatal/birth/neonatal care or gestational diabetes. Using a “sailboat” analogy, we develop the general and specific characteristics that enhance intervention acceptability within this context and setting. All studies reported positive significant improvements in maternal health knowledge post-intervention, illustrating that paper-based, digital, and melody-based tools can attribute positive impacts. It is important to note the limitations in study quality and KT tool reporting when considering the magnitude of these findings.

The “gems” gleaned from this research include the general and specific features that contributed to intervention acceptability. These include the general features of: 1) trusted tool delivery; 2) the packaging of empowering, motivating, and myth dispelling evidence-based health messages; 3) simple, structured, co-ordinated, and visually reinforced design that has been pilot-

tested. Within these major categories, the specific features that are particularly nuanced for this population include: 1) increasing trusted delivery by using female voice artists (to emulate trusted and amicable female relatives); 2) integrating family-centric messaging; 3) adapt designs to local practices, cultural factors, and use familiar melodies to supplement audio-visuals.

The introduced “gaps” relate to not all studies reporting or assessing their processes for intervention design and development. Although many studies were based upon community-based approaches or internal formative research, the use of theory was rarely reported. This finding parallels other evidence that reports the lack of theory-informed conceptual work when designing KT interventions (Strifler et al., 2018). To better support and help researchers, clinicians, and policy-makers in selecting appropriate theories, Esmail et al., (2020) provide a consolidated compendium of full-spectrum options. Future research should include understanding, utilizing, and evaluating KT theories to improve the design, implementation, and modification of tools. In all cases, these KT tools were evaluated against a standard care control. As a next step, it would be useful for these tools to be evaluated against other KT tools to establish a course of direction in regard to effectiveness, patient experiences, and healthcare costs.

The strengths of this study include the comprehensive literature search strategy across three key databases and grey literature, a priori guidance of methods and critical appraisal, study selection conducted in duplicate, the transparent provision of excluded studies, and the collation of study findings using an analogy. Limitations of this study including the inclusion of only English-language studies and not incorporating the study-level risk of bias assessments as a critical lens when exploring the results of this review. Interesting and surprisingly, no studies conducted in high income countries such as Canada or comparable health contexts were located on this topic.

With South Asian communities being the fastest growing population in many high-income countries (e.g., Canada), we need to better understand their specific perinatal knowledge needs so that effective and inclusive healthcare care be provided (including perinatal health inequities). Furthermore, with certain prenatal health conditions, such as gestational diabetes, potentially impacting downstream health burdens upon this population (Anand et al., 2017), we are further in need of effective behaviour change communication tools and strategies. The pregnancy ecology illuminates the idea that although each individual is unique, in general, pregnant women are highly invested in behaviour change due to the concern they have about the future health of their unborn child (Kraschnewski et al., 2013; Szwajcer et al., 2012). As a result, pregnancy becomes a crucial time period to intervene and thus, an important consideration for behaviour change communication and KT tools. It is also a time period where a woman's information-seeking needs are heightened, giving such interventions a platform to stand upon. Pregnancy has been shown to be a "teachable moment" where effective health practices can not only reduce healthcare costs, but also downstream health complications for both the mother and the child. If this crucial time period is bridged with the effective components of behaviour change communication interventions, we are better equipped to design effective tools and programs, including tailoring and sustaining behaviour change.

## **6.0 Conclusion**

South Asian women encompass a diverse global community who experience unique socio-cultural climates around pregnancy and birth. Studying the components of KT tools targeting this population may allow for a better direction on future intervention design, development, and evaluation. We use an analogy to enumerate general and specific features that impact knowledge,



perception, and/or behaviour change: type of information, quality of information, and delivery of information. These elements can be implemented to design better suited interventions for pregnant South Asian women and their family support systems across different geographies and contexts. It is vital that KT tools continue to be theory-informed and evidence-based. Corresponding implementation efforts for this priority population should continue to be evaluated in various contexts, including high-income countries.

## FIGURES

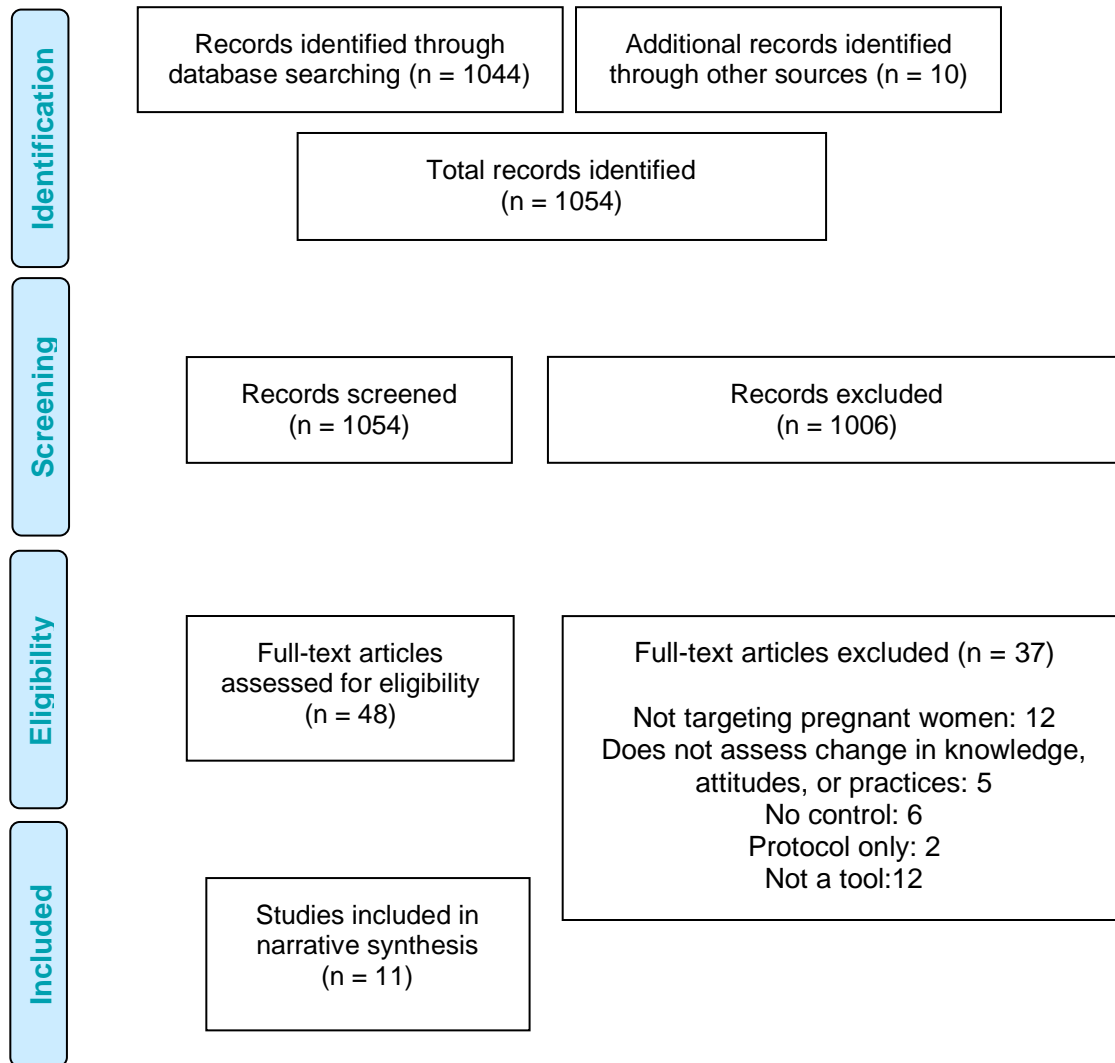


Figure 1. PRISMA diagram of search outputs

## TABLES

	General characteristics of tools	Specific characteristics relevant for pregnant South Asians
Who should deliver the tool?	A trusted individual from the community (healthcare worker) (Ilozumba et al., 2018b; Khan et al., 2013; Murthy et al., 2019)	Audio tools may have increased trust and uptake if voice artist has a female-sounding voice (Murthy et al., 2019)
What types of messages should be included in the tool?	Supportive information that motivates and empowers behaviour change (John et al., 2015; Josan et al., 2015; Shivalli et al., 2015)  Dispelling myths and fears (John et al., 2015)	Family-centric messages (Shivalli et al., 2015)
How should the tool be delivered?	In simple language (Ayekpam et al., 2011)  Using simple explanations (Ayekpam et al., 2011)  Visuals that reinforce text-based messages (Ayekpam et al., 2011; Shivalli et al., 2015) Accessible mobile technology (Chowdhury et al., 2015; Ilozumba et al., 2018a; Ilozumba et al., 2018b) Structured design (Josan et al., 2015)  Timing messages to correspond with trimester to better ensure relevance (Murthy et al., 2019) to  Pilot-tested messages and tools (Murthy et al., 2019)  Re-iterating of key messages (Murthy et al., 2019; Shivalli et al., 2015)	Adaptation to local practices (Murthy et al., 2019; Parashar et al., 2013; Sharma et al., 2018)  Incorporation of cultural nuances (Murthy et al., 2019; Sharma et al., 2018)  Use of familiar jingles/melodies to remind women of key messages (Sharma et al., 2018)

Table 1. Key intervention characteristics

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## Appendix 1: Search Strategy

Database: OVID Medline Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

- 
- 1 knowledge translation.mp. or Translational Medical Research/ (13405)
  - 2 implement\*.mp. (506349)
  - 3 "Diffusion of Innovation"/ or Health Promotion/ or Information Dissemination/ or knowledge exchange.mp. or Public Health/ or Knowledge/ (194757)
  - 4 knowledge transfer.mp. (1952)
  - 5 Evidence-Based Practice/ or research utilization.mp. (10833)
  - 6 disseminat\*.mp. (152086)
  - 7 Diffusion/ or diffus\*.mp. or "Diffusion of Innovation"/ (441463)
  - 8 applied health research.mp. (155)
  - 9 Communication/ or knowledge communicat\*.mp. (84574)
  - 10 knowledge cycle.mp. (8)
  - 11 knowledge management.mp. or Knowledge Management/ (1440)
  - 12 knowledge mobilization.mp. (94)
  - 13 knowledge into practice.mp. (336)
  - 14 research into practice.mp. (967)
  - 15 (linkage and exchange).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (2501)
  - 16 research mediation.mp. (2)
  - 17 science communicat\*.mp. (719)
  - 18 translational research.mp. or Translational Medical Research/ (19170)
  - 19 patient education.mp. or Patient Education as Topic/ (101184)
  - 20 Health Promotion/ or mass communication.mp. (74376)
  - 21 public health/ or applied health research.mp. or evidence based practice/ (91946)
  - 22 pregnan\*.mp. (1010848)
  - 23 gestation\*.mp. (249108)
  - 24 matern\*.mp. (341297)
  - 25 south asian\*.mp. (5986)
  - 26 Asian Continental Ancestry Group/ or Asian heritage.mp. (65641)
  - 27 exp INDIA/ or india\*.mp. (220004)



28 exp BANGLADESH/ or bangladesh\*.mp. (16620)  
 29 exp NEPAL/ or nepal\*.mp. (12441)  
 30 exp PAKISTAN/ or pakistan\*.mp. (26987)  
 31 exp Sri Lanka/ or sri lanka\*.mp. (9078)  
 32 bengali\*.mp. (447)  
 33 indo asian\*.mp. (145)  
 34 indoasian\*.mp. (3)  
 35 Asia, Southeastern/ or Asian Continental Ancestry Group/ or Southeast Asian.mp. (75795)  
 36 Knowledge/ or knowledg\*.mp. (784708)  
 37 Attitude/ or Attitude to Health/ or attitud\*.mp. (428639)  
 38 perspective\*.mp. (327552)  
 39 Health Knowledge, Attitudes, Practice/ or belief\*.mp. (183446)  
 40 behaviour\*.mp. (289949)  
 41 behavior\*.mp. (1478329)  
 42 literacy.mp. or Literacy/ or Health Literacy/ (23458)  
 43 community health.mp. or Public Health/ (161908)  
 44 Early Intervention, Educational/ or Internet-Based Intervention/ or Early Medical Intervention/ or Intervention.mp. (631249)  
 45 Program Evaluation/ or Evaluation Studies as Topic/ or evaluation.mp. or Evaluation Study/ (1666870)  
 46 Models, Theoretical/ or framework\*.mp. (426196)  
 47 assess\*.mp. (3341950)  
 48 Evaluation Studies as Topic/ or Program Evaluation/ or Program Evaluat\*.mp. (188638)  
 49 cycle.mp. (537388)  
 50 theor\*.mp. (857432)  
 51 implement.mp. (71250)  
 52 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (1403907)  
 53 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 (348027)  
 54 36 or 37 or 38 or 39 or 40 or 41 or 42 (2866587)  
 55 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 (6401407)  
 56 prenat\*.mp. or Prenatal Care/ (178701)  
 57 22 or 23 or 24 or 56 (1214318)  
 58 52 and 53 and 54 and 55 and 57 (705)  
 59 limit 58 to yr="2010 -Current" (461)

\*\*\*\*\*

Database: Ovid Emcare <1995 to 2020 Week 37>

Search Strategy:

- 
- 1 knowledge translation.mp. or Translational Medical Research/ (5826)
  - 2 implement\*.mp. (244546)
  - 3 "Diffusion of Innovation"/ or Health Promotion/ or Information Dissemination/ or knowledge exchange.mp. or Public Health/ or Knowledge/ (163917)
  - 4 knowledge transfer.mp. (1260)
  - 5 Evidence-Based Practice/ or research utilization.mp. (46374)
  - 6 disseminat\*.mp. (47437)
  - 7 Diffusion/ or diffus\*.mp. or "Diffusion of Innovation"/ (87657)
  - 8 applied health research.mp. (104)
  - 9 Communication/ or knowledge communicat\*.mp. (84290)
  - 10 knowledge cycle.mp. (8)
  - 11 knowledge management.mp. or Knowledge Management/ (1749)
  - 12 knowledge mobilization.mp. (69)
  - 13 knowledge into practice.mp. (269)
  - 14 research into practice.mp. (758)
  - 15 (linkage and exchange).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] (223)
  - 16 research mediation.mp. (2)
  - 17 science communicat\*.mp. (171)
  - 18 translational research.mp. or Translational Medical Research/ (4983)
  - 19 patient education.mp. or Patient Education as Topic/ (42437)
  - 20 Health Promotion/ or mass communication.mp. (52394)
  - 21 public health/ or applied health research.mp. or evidence based practice/ (141849)
  - 22 pregnan\*.mp. (189928)
  - 23 gestation\*.mp. (81310)
  - 24 matern\*.mp. (119715)
  - 25 south asian\*.mp. (3417)
  - 26 Asian Continental Ancestry Group/ or Asian heritage.mp. (77)
  - 27 exp INDIA/ or india\*.mp. (61032)
  - 28 exp BANGLADESH/ or bangladesh\*.mp. (6367)
  - 29 exp NEPAL/ or nepal\*.mp. (4260)
  - 30 exp PAKISTAN/ or pakistan\*.mp. (7440)
  - 31 exp Sri Lanka/ or sri lanka\*.mp. (2690)
  - 32 bengali\*.mp. (179)

33 indo asian\*.mp. (61)  
 34 indoasian\*.mp. (2)  
 35 Asia, Southeastern/ or Asian Continental Ancestry Group/ or Southeast Asian.mp. (3097)  
 36 Knowledge/ or knowledg\*.mp. (287067)  
 37 Attitude/ or Attitude to Health/ or attitud\*.mp. (184109)  
 38 perspective\*.mp. (154171)  
 39 Health Knowledge, Attitudes, Practice/ or belief\*.mp. (68015)  
 40 behaviour\*.mp. (115698)  
 41 behavior\*.mp. (519224)  
 42 literacy.mp. or Literacy/ or Health Literacy/ (17743)  
 43 community health.mp. or Public Health/ (110923)  
 44 Early Intervention, Educational/ or Internet-Based Intervention/ or Early Medical Intervention/ or Intervention.mp. (370635)  
 45 Program Evaluation/ or Evaluation Studies as Topic/ or evaluation.mp. or Evaluation Study/ (478314)  
 46 Models, Theoretical/ or framework\*.mp. (136212)  
 47 assess\*.mp. (1491819)  
 48 Evaluation Studies as Topic/ or Program Evaluation/ or Program Evaluat\*.mp. (13804)  
 49 cycle.mp. (113804)  
 50 theor\*.mp. (224164)  
 51 implement.mp. (36586)  
 52 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (644497)  
 53 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 (82889)  
 54 36 or 37 or 38 or 39 or 40 or 41 or 42 (1067768)  
 55 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 (2345168)  
 56 prenat\*.mp. or Prenatal Care/ (56260)  
 57 22 or 23 or 24 or 56 (284272)  
 58 52 and 53 and 54 and 55 and 57 (492)  
 59 limit 58 to yr="2010 -Current" (411)

## Appendix 2: Supplementary Tables

First Author, Year	Location	Objectives of evaluation	Methodology used for evaluation	Description of Implementation tool	Frequency of delivery	Antenatal population	Results	Key take-aways regarding tool
Ayekpam et al., 2011	Udupi District, Karnataka State, India	To determine the following: 1) the knowledge level of the antenatal mothers on newborn danger Signs; 2) the effectiveness of an information booklet on newborn danger signs in terms of gain in post-test knowledge scores; 3) the association between pretest knowledge scores on newborn danger signs and selected variables; 3) to obtain antenatal mother's opinion on acceptability of the information booklet on newborn danger signs	Pre-test/Post-test using a structured knowledge questionnaire. The significant difference between pre-test knowledge and post-test knowledge was computed using Wilcoxon signed rank test	Information booklet	One time	n=54	There was a statistically significant gain the post-test knowledge scores	Strengths: booklet as a good source of learning, simple language, easy to understand, content explained in simple form, booklet style can help mothers learn in their own free time, pictures reinforced content
Chowdhury et al., 2019	Surrounding urban, rural, and slum communities of Dhaka, Bangladesh	To test the effectiveness of a mobile health intervention (Aponjon) which used interactive voice messages to improve knowledge of maternal and newborn health	Retrospective observational study of users and non-users of Aponjon	Mobile phone-based service for expectant and new mothers to receive behaviour change communication messages quickly and easily.  Messages were tailored to the point in pregnancy and	2 new messages per week. Subscribers could listen to previous messages or the same message repeatedly.	n=3225	Women reporting at least 6 months of Aponjon use were 3 times and 1.5 times as likely to score high on maternal knowledge and practice questions and newborn knowledge and practice questions, respectively	Strengths: use of mobile technology  Improvements: incentivizing free of charge service, allowing users to select preferred times for receiving messages

				focused on dispelling myths/misconceptions, building awareness of warning signs, post-partum feeding, nutritional intake.				
Ilozumba et al., 2018a (quantitative)	Deoghar district, Jharkhand, India	To achieve the following: 1) improve the delivery of services of CHWs to pregnant women, specifically by providing information and referral services; 2) increase the knowledge and health-seeking behavior of pregnant women in selected rural communities; and 3) improve the collection of key health indicators related to safe motherhood	Quasi-experimental cross-sectional study	Each health worker received a mobile phone equipped with multi-media functions (text, pictures, voice prompts) to use during home clinic visits.	Minimum 1 to >4 times	n=4400	Tool led to higher maternal health knowledge, increased likelihood of participating in >4 antenatal visits	Mobile health interventions can help overcome engagement barriers related to socio-economics/geography  Challenges: overcoming social determinants of maternal health that are specific to the population and context (e.g., caste)
Ilozumba et al., 2018b (qualitative)				Content included registration forms, checklists, danger sign monitoring, educational prompts. Technological features included voice-based text processions, alert functions, storage of data on the mobile device			Overall response to the intervention was positive as it improved healthcare workers' perceptions of confidence and performance of maternal health related tasks by providing a systematic source for information delivery	Challenges: Contextual factors such as the trust level between the healthcare worker and the community, the pregnant woman's locus of control, and financial barriers impacted the success of the intervention.  Contextual factors such as the women's responsibilities for the home, the need to arrange childcare during clinic visits/ delivery and the positioning of men and mother-in-laws as key decision makers.
John et al., 2015	Meerut, Uttar Pradesh, India	To evaluate the effectiveness of a video-assisted childbirth program ("guided imagery") on childbirth knowledge using a 60-question survey	Pre-experimental study with pre-test and post-test design with evaluative approach	Teaching video	1 time	n=50	Antenatal knowledge increased significantly post intervention	Strengths: supportive information, dispelling of fears/misconceptions
Josan et al., 2015	Jalandhar, Punjab, India	To evaluate the effectiveness of a structured teaching	Pre-experimental study with	Structured paper-based teaching tool	1 time	n=60	Mean percentage of the knowledge score	Strengths: focus on GDM, structured teaching design, motivation/empowerment of patients

		tool on GDM knowledge using a 30-question survey	pre-test and post-test design with evaluative approach				post-test was higher than pre-test	
Khan et al., 2013	Aligarh, India	To assess the behaviour of pregnant women regarding neonatal care and to implement and evaluate the impact of a behaviour change communication package	Community-based intervention study	Self-designed pamphlets containing simple messages	1 time	n=200	Knowledge on newborn danger signs were increased in addition to delivery practices	Strengths: delivery by trusted community-based health workers.  Challenges: difficulty of overcoming cultural practices, beliefs, and influence of elder women in the family
Murthy et al., 2019	Urban slum areas of Mumbai, India	To evaluate the impact of an age and stage-based mobile health voice messaging tool on improving pregnant women's infant care knowledge and practices	Pseudo-randomized controlled trial	Mobile-health tool that provides women with educational messages that are interesting, easy to understand, and aligned with the physiological stage of pregnancy (6 weeks gestation to 1 year post-partum).	2 messages per week (145 voice messages total)	n=2000	Tailored health messages delivered via mobile tool can significantly improve maternal health knowledge and infant care practices	Strengths: timing to gestational age, adaptation to local practices, translations/cultural nuances tested for appropriateness, female voice artist generated messages were field tested prior to use (trusting voice), each message began with a characteristic "jingle" and ended with re-iterating the key message
Parashar et al., 2013	Gokulpuri, Delhi, India	To assess the effect of a behaviour change communication tool on neonatal care	Community-based intervention study with standard care control	The tool was a series of messages on different neonatal care topics, including counselling, posters, pamphlets, and demonstration	Not stated	n=200	The intervention significantly improved delivery practices and maternal knowledge and reduced harmful practices	Strengths: responding to the specific needs of the local community
Sharma et al., 2018	Chitre, Ramja Deurali, Mudikuwa, Falebas, and	To assess the effectiveness of transmitting antenatal health	Randomized Control Trial	The tool included health messages packaged in the form of songs and a Holy Duty wall	80 singing sessions were organized and facilitated	n=1572	Post-intervention knowledge scores doubled (no change in control). 1-year post-intervention, 63%	Strengths: development and implementation under local leadership, tailored culturally appropriate model of health info translation, melody-based messaging bypassed literacy limitations

	Khanigaun Village Development Committees, Nepal	messages in the form of songs		chart that illustrated the key health messages from the songs			indicated they provided information they learned to neighbours/friends and 41% still sang the songs from the intervention	
Shivalli et al., 2015	Villages in Varanasi, India	To examine the effectiveness of the intervention on dietary intake during pregnancy	Community-based quasi-experimental study with a control group	The tool was tailored to each individual based on the results of an assessment visit. The communication/co unselling guide and home-based reminder materials contained health messages and pictures for visual reinforcement.	1 visit to provide the tools	n=86	Nutritional status (i.e., increased protein consumption, reduction in anemia) improved in the intervention group	Strengths: interpersonal communication, empowering family members, home-based reminder materials, encouraging messaging, visual reinforcements

Table 1. Description of all included studies

Study design	First Author (year)	KT Tool	Primary outcomes			
			Patient's knowledge	Patient's experiences	Service utilization/costs	Health practices/status
Pre-test/Post-test	Ayekpam et al., 2011	Information booklet	+	+	Not assessed	Not assessed
	John et al., 2015	Teaching video	+	Not assessed	Not assessed	Not assessed
	Josan et al., 2015	Structured paper-based teaching tool	+	Not assessed	Not assessed	Not assessed
Cross-sectional	Ilozumba et al., 2018a/b	Mobile-phone based tool	+	+	Not assessed	Mixed
Observational study with control	Chowdhury et al., 2019	Mobile-phone based voice messages	+	Not assessed	Mixed	Mixed
	Khan et al., 2013	Self-designed pamphlets containing simple messages	Mixed	Not assessed	Not assessed	Mixed
	Parashar et al., 2013	Counselling, posters, pamphlets, and live demonstration	Mixed	Not assessed	Not assessed	Mixed
Quasi RCT	Murthy et al., 2019	Mobile-phone based messages	Mixed	Not assessed	Not assessed	Mixed
	Shivalli et al., 2015	Communication/counselling guide and home-based reminder materials	Not assessed	+	Not assessed	+
RCT	Sharma et al., 2018	Health songs and a Holy Duty wall chart that illustrated the key health messages from the songs	+	+	Not assessed	Not assessed

Table 2. Summary of outcomes for patient-focused interventions (+ represents increased)



### Appendix 3: Risk of Bias Assessments

Domain	Assessment
Random sequence generation	High
Allocation concealment	High
Selective reporting	Low
Other sources of bias	High

Table 3. Cochrane Risk of Bias Assessment (Sharma et al., 2018). Notes: coin toss used to allocate villages to either intervention or control; high risk of contamination and efforts to minimize not reported; outcomes were reported as listed

#### QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES (Effective Public Health Practice Project)

##### A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population? 1 Very likely 2 Somewhat likely 3 Not likely 4 Can't tell

Q2) What percentage of selected individuals agreed to participate? 1 80 - 100% agreement 2 60 – 79% agreement 3 less than 60% agreement 4 Not applicable 5 Can't tell

##### B) STUDY DESIGN

Indicate the study design 1 Randomized controlled trial 2 Controlled clinical trial 3 Cohort analytic (two group pre + post) 4 Case-control 5 Cohort (one group pre + post (before and after)) 6 Interrupted time series 7 Other specify \_\_\_\_\_ 8 Can't tell

##### C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention? 1 Yes 2 No 3 Can't tell

The following are examples of confounders: 1 Race 2 Sex 3 Marital status/family 4 Age 5 SES (income or class) 6 Education 7 Health status 8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)? 1 80 – 100% (most) 2 60 – 79% (some) 3 Less than 60% (few or none) 4 Can't Tell

##### D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants? 1 Yes 2 No 3 Can't tell

(Q2) Were the study participants aware of the research question? 1 Yes 2 No 3 Can't tell

## **E) DATA COLLECTION METHODS**

(Q1) Were data collection tools shown to be valid? 1 Yes 2 No 3 Can't tell

(Q2) Were data collection tools shown to be reliable? 1 Yes 2 No 3 Can't tell

## **F) WITHDRAWALS AND DROP-OUTS**

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group? 1 Yes 2 No 3 Can't tell 4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest). 1 80 -100% 2 60 - 79% 3 less than 60% 4 Can't tell 5 Not Applicable (i.e. Retrospective case-control)

## **G) INTERVENTION INTEGRITY**

(Q1) What percentage of participants received the allocated intervention or exposure of interest? 1 80 -100% 2 60 - 79% 3 less than 60% 4 Can't tell

(Q2) Was the consistency of the intervention measured? 1 Yes 2 No 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results? 4 Yes 5 No 6 Can't tell

## **H) ANALYSES**

(Q1) Indicate the unit of allocation (circle one) community organization/institution  
practice/office individual

(Q2) Indicate the unit of analysis (circle one) community organization/institution practice/office  
individual

(Q3) Are the statistical methods appropriate for the study design? 1 Yes 2 No 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received? 1 Yes 2 No 3 Can't tell

First Author (Year)	<b>Recommendation 1</b> Detailed description of the intervention								<b>Recommendation 2</b> Clarification of assumed change process and design principles			<b>Recommendation 3</b> Access to intervention manuals/protocols	<b>Recommendation 4</b> Detailed description of active control conditions
Ayekpam et al., 2011	1	2	3	4	5	6	7	8	A	B	C	No	NOT APPLICABLE (PRE/POST)
John et al., 2015	1	2	3	4	5	6	7	8	A	B	C	No	NOT APPLICABLE (PRE/POST)
Josan et al., 2015	1	2	3	4	5	6	7	8	A	B	C	No	NOT APPLICABLE (PRE/POST)
Ilozumba et al., 2018a/b	1	2	3	4	5	6	7	8	A	B	C	No	1 2 3 4 5 6 7 8
Chowdhury et al., 2019	1	2	3	4	5	6	7	8	A	B	C	No	NOT APPLICABLE (NOT ACTIVE CONTROL)
Khan et al., 2013	1	2	3	4	5	6	7	8	A	B	C	No	1 2 3 4 5 6 7 8
Parashar et al., 2013	1	2	3	4	5	6	7	8	A	B	C	No	1 2 3 4 5 6 7 8
Murthy et al., 2019	1	2	3	4	5	6	7	8	A	B	C	No	1 2 3 4 5 6 7 8
Shivalli et al., 2015	1	2	3	4	5	6	7	8	A	B	C	No	1 2 3 4 5 6 7 8
Sharma et al., 2018	1	2	3	4	5	6	7	8	A	B	C	No	1 2 3 4 5 6 7 8

Table 4. WIDER Recommendations Checklist

WIDER items 1: characteristics of those delivering the intervention, 2: characteristics of the recipients, 3: the setting, 4: the mode of delivery, 5: the intensity, 6: the duration, 7: adherence/fidelity to delivery protocols, 8: detailed description of the intervention content provided for each study group, A: the intervention development, B: the change techniques used in the intervention, C: the causal processes targeted by these change techniques. The shaded boxes represent the components that were assessed within the description of the respective publication.

**CHAPTER 4:**  
**GETTING A ‘SMART START’ TO A HEALTHY PREGNANCY:**  
**DESCRIBING THE PROCESS OF DEVELOPING A THEORY-INFORMED,**  
**EVIDENCE-BASED MULTI-MEDIA KNOWLEDGE TRANSLATION TOOL TO**  
**PROMOTE HEALTHY ACTIVE LIVING AMONG PREGNANT SOUTH ASIAN**  
**WOMEN**

Getting a ‘SMART START’ to a healthy pregnancy:  
Describing the process of developing a theory-informed, evidence-based multi-media knowledge  
translation tool to promote healthy active living among pregnant South Asian women

**Abstract**

There are high rates of gestational diabetes among South Asians in Ontario, Canada. Current adherence to healthy dietary practices and physical activity guidelines is low in this group, possibly related to gaps in evidence-based, culturally tailored Knowledge Translation (KT) tools. To lower and prevent gestational diabetes among South Asians, there is a need for patient-centered interventions that strengthen early prevention dialogue between patients and prenatal clinicians. KT tools can empower patients to make healthy lifestyle choices when they weave together theoretical frameworks with empirical work that includes local need (patient experiences), contextual considerations, and arts-based designs (engaging elements). The description of how we established the ‘SMART START’ KT tool can be used as a case study for developing a timely KT strategy that addresses a public health challenge in a priority population.

## Introduction

Gestational diabetes mellitus (GDM) is high blood sugar during pregnancy, typically diagnosed between 24-28 weeks gestation. Pregnancies affected by GDM are more likely to be affected by fetal macrosomia, greater infant skinfold thickness, delivery complications, neonatal hypoglycemia and hyperbilirubinemia, increased future risk of type 2 diabetes and other cardiovascular disease risk for both the mother and the newborn (HAPO Study Cooperative Research Group, 2008; Vohr & Booney 2008; Aceti et al., 2012; Kim et al., 2011; Anand et al., 2017; Kramer et al., 2019). The incidence of GDM is increasing worldwide with a global prevalence estimated at around 16.9% (Guariguata et al., 2014). This is expected to increase as more women enter pregnancy at older ages and higher body weights. South Asian immigrants to high-income countries (such as Canada) are considered a priority population as they are disproportionately affected by GDM, with an incidence of approximately 36% (Anand et al., 2017). Risk factors for the condition in South Asians include higher maternal age, a family history of diabetes, higher pre-pregnancy weight, and low diet quality (Anand et al., 2017).

A recent systematic review of women's experiences with a GDM diagnosis describe 1) the initial psychological burden (e.g., self-blame, failure, fear, sadness); 2) mixed level and quality of communication with health care providers about the diagnosis (e.g., challenges included the use of overly technical language, unsupportive consultations, limited time, lack of continuity of care, lack of understanding about the role of the HCP at follow-up); 3) challenges associated with a lack of knowledge (including about GDM screening and impacts on the unborn child); and 4) burden of management (Craig et al., 2020). Although benefits of a GDM diagnosis include an opportunity to improve health, prevent excessive weight gain, and prompts to make healthy eating changes, the harms included an added responsibility (eating regimens, appointments), financial constraints

(expensive food), and conflicts with cultural practices (alternative eating, lack of information about traditional food) (Craig et al., 2020). The psychosocial consequences are also wide reaching and often cause social isolation as women only share their diagnosis with partners in some cases (Craig et al., 2020). Among South Asian women specifically, prenatal dietary advice was met with barriers associated with culturally-specific food habits and differing attitudes related to physical activity (Bandyopadhyay et al., 2011). Additionally, the economic burden associated with GDM remains substantial, with a recent model predicting that the overall cost of care for an individual with GDM is 34% greater compared to a pregnant person without the diagnosis (Gillespie et al., 2013). New interventions that prevent or reduce GDM risk must be identified and implemented (Agha-Jaffar et al., 2016).

Over 30 randomized control trials on GDM prevention have been reported (Feig et al., 2018). Interventions to date include dietary approaches, diverse physical activity plans, provision of supplements and dietary products (e.g., vitamin D, probiotics), and metformin, either individually or in combination. Among tested approaches, interventions related to healthy eating have consistently demonstrated significant reductions in GDM, but mixed-approach interventions have only demonstrated effectiveness if introduced before 15 weeks of gestation, and overall, there is limited evidence that lifestyle, physical activity programs, metformin, or vitamin D supplementation prevents GDM (Madhuvrata et al., 2015; Rogozinska et al., 2015; Song et al., 2016). The provision of dietary knowledge has largely been done using dietician-led counselling efforts. However, these personalized approaches come with limitations related to scaling and population-level impact. To address this within Canada, organizations such as Diabetes Canada, the Heart and Stroke Foundation, and Eat Right Ontario have developed tailored resources for larger scale distribution. However, in general, limited approaches have been customized to address

the experiences and perspectives of specific ethnic groups, literacy levels, or based on unique biological risk factor profiles. Nutritional information received during healthcare appointments are also described as confusing and constantly changing, and with food being a cornerstone of cultural identity and membership, specific culturally significant foods may be harder to avoid or substitute (Vanstone et al., 2017). The lack of scalable culturally-relevant approaches tailored for pregnant South Asians was demonstrated in a local needs assessment of patient and healthcare provider experiences (Kandasamy et al., 2020) and the call for additional resources have been amplified by others (Greenhalgh et al., 2015; de Sequeira et al., 2019).

Translating, applying, and socializing research into practice (e.g., packaging evidence in an appetizing resource or tool) sprouts its roots in Knowledge Translation (KT), a dynamic and growing field that guides the push of evidence into practice (Straus et al., 2011). To increase uptake, KT researchers have contributed over 150 different KT models, theories, and frameworks. However, studies illustrate that researchers designing interventions often fail to use this base of KT knowledge, or use them accurately (Striffler et al., 2018). This lack of theory-informed work paired with a need for innovative and culturally-relevant KT tools propel the objectives of this project. To help minimize these gaps, we aimed to apply and report upon the frameworks, principles, and evidence used to design a culturally-relevant GDM KT tool for pregnant South Asians and their family physicians.

## **Description**

We developed a theory-informed and evidence-based, multi-media KT tool (‘SMART START’). Our design approach is informed by the Knowledge-To-Action framework, an expanded version of the health belief model, and the Canadian Medical Education Directions for Specialists (CanMEDS) Family Physician competency framework; and empirically informed by



local longitudinal birth cohort data, formative qualitative work, and arts-based KT principles. We describe these components in greater detail in the sections below (See Table 1 for a summary).

‘SMART START’ includes two parallel versions, one for patients (pregnant South Asians) and one for primary prenatal healthcare providers (family physicians who conduct early prenatal clinic visits with pregnant South Asians). The patient tool includes the following culturally-tailored and lay-language components: 1) a short digital narrative to contextualize the GDM challenge and to spark interest; 2) pocket-sized guidebook with personalized elements, suggested queries to consider, and community resources; 3) summary reminder material in the form of a compact fridge magnet. The provider facing version consists of a laminated summary card with evidence-based information, suggested scripts, and links to additional resources. The tools come as a set, where the family physician distributes the patient version and uses it as an opportunity to contextualize their lifestyle counselling (See Appendix 1 and 2 for copies of both tools).

***Theory-Informed: The use of frameworks in the development of the ‘SMART START’ KT tool***

The design of this KT tool was rooted in principles outlined by 1) the Knowledge-to-Action (KTA) framework proposed by Graham et al., (2006), 2) the CanMEDS physician competency framework for Family Physicians developed by Shaw et al., (2017), and 3) an expanded version of the health belief model developed by Rosenstock, Strecher, & Becker (1988).

The KTA framework is composed of two dynamic parts: knowledge creation and action. Using this framework, we identified the problem/practice gap to be a limited availability of culturally-relevant healthy active living KT tools for pregnant South Asians. To develop a relevant

KT tool, we focused on addressing local contextual considerations, assessing barriers to uptake, and tailoring tools to our key audiences (see Section A, Table 1).

In addition, the patient-facing version is complemented with components of Behaviour Change Communication (BCC) Theory, via a modified version of the health belief model. This model posits that health messaging will achieve optimal behaviour change if perceived barriers, benefits, self-efficacy, and threats are successfully targeted and communicated (Rosenstock, 1974; Champion & Skinner, 2008). This model emphasizes that perceived susceptibility and severity contribute to perceived threat. Paired with perceived benefits and barriers and cues to action, these three components modify preventative health behaviours. ‘SMART START’ amplifies these components to improve knowledge, attitudes, and practices that may encourage healthy active lifestyles as an avenue for GDM prevention (‘SMART START’ is positioned to hold a deep focus on healthy eating with some guidance around physical activity). For example, to address perceived threat, we incorporated a visualization of risk using a percentage diagram, and education around modifiable and non-modifiable risk factors. To address perceived benefits and barriers, we highlight practices that have the potential to prevent GDM and its complications (e.g., staying within gestational weight range, engaging in healthy active lifestyles, consuming healthy balanced diet), assistance in identifying barriers to action (via the suggestions questions/dialogue to have with healthcare providers). To bring attention to cues to action, we present new knowledge about GDM, promotion of GDM screening, operationalizable tips/tricks related to dietary changes, and inclusion of easy and healthy recipes (See Section B, Table 1).

The family physician facing version was developed with the intention of improving lifestyle counselling experiences for both patients and primary care physicians via the CanMEDS physician competency framework for Family Physicians (Shaw et al., 2017). CanMEDS is a

framework that identifies and describes the abilities physicians require to effectively meet the health care needs of the people they serve. These abilities are grouped thematically under seven roles: collaborator, leader, health advocate, scholar, professional, and communicator. ‘SMART START’ emphasizes the key components of the communication, health advocacy, and scholar roles. As communicators, family physicians facilitate doctor-patient relationships and dynamic exchanges that are necessary for upholding patient-centered healthcare (Shaw et al., 2017). This can be applied to ‘SMART START’ by encouraging family physicians to demonstrate an understanding of patient experiences (ideas, sentiments, expectations) by asking open-ended questions to better tailor guidance in a patient/family-centered way. Despite abilities, cultural differences, age, and challenging situations, family physicians aim to uphold effective communication. The basic competencies of this role are fundamental in establishing trust, delivering information, mutual understanding, and co-creating a shared plan of care (Shaw et al., 2017). As health advocates, family physicians use their expertise and influence to advocate for the health of patients, communities, and populations (Shaw et al., 2017). As scholars, family physicians demonstrate a lifelong commitment to the dissemination, application, and translation of knowledge. This includes facilitating the education of patients and families, integrating best available evidence into practice (with consideration of context, epidemiology, comorbidities, and the complexity of patients), and appropriately disseminating the findings of scholarly research that are relevant to family medicine (including participation in quality-improvement activities and communicating relevant research in lay terms) (Shaw et al., 2017). ‘SMART START’ provides an opportunity to enhance patient-centred communication and to integrate culturally-safe care using evidence-based tools (See Section C, Table 1).

### **Evidence-based: the use of empirical data in the development of ‘SMART START’**

The empirical work that informed the development of this KT tool includes: 1) local need and contextual considerations; and 2) a review of the evidence as it pertains to arts-based KT and design elements.

*Local need and contextual considerations:* In addition to the global literature on the disproportionate impact of GDM on ethnic minorities, GDM risk factors, and the growing economic burden of this condition, recent evidence from our local context of the Peel Region, Ontario, Canada illustrates that the disproportionately high rates of GDM among South Asian women should be a priority for clinicians, patients, and the healthcare system. Specifically, our recent data from the South Asian Birth Cohort study demonstrates that over one third of South Asian women are diagnosed with GDM and that pre-pregnancy weight and low-quality diet accounted for 37% of GDM cases (Anand et al., 2017). ‘SMART START’ integrates the specifics around modifiable and unmodifiable risk factors and components of high-quality foods that are pertinent to this priority population. Furthermore, we completed a local needs assessment to qualitatively explore the perspectives and experiences of South Asians and healthcare practitioners living and working in the Peel Region. This work demonstrated the local need for the following: 1) culturally-relevant health resources that are packaged as small, pocket-sized printed booklets; 2) early provision of resources and counselling (i.e., during the early stages of the first trimester); and 3) relatively seamless integration into the family practice environment (Kandasamy et al., 2020). ‘SMART START’ was developed using these suggestions as the foundation. With guidance from our theoretical work, we then built upon these key suggestions by using them as design reference points. To better understand how to develop these suggestions into effective patient-

centered tools, we turned to the literature on arts-based KT, design elements, and partnerships with artists and illustrators.

*Incorporation of arts-based KT and design elements:* Arts-based KT strategies are increasingly becoming viable means of engagement by providing evidence-based products and tools in palatable, culturally-tailored, and lay-language formats (Archibald et al., 2014; Archibald et al., 2019). These approaches combine non-academic modes of communication such as digital media (e.g., videos, short films, infographics) and artistic expressions (e.g., story-telling) to redress traditional KT outcomes such as changes in knowledge, attitudes, and behaviour modification practices (Alberta Addiction & Mental Health Research Program, 2015). Design elements that relate to the efficient use of language, readability, typography, graphics and illustrations, layout, space, paper selection, and audience relevancy can improve the quality of patient education tools (Strachan et al., 2012; Centers for Disease Control and Prevention, 2009; US Department of Health and Human Services, 1994). With the support of patient and physician feedback, the primary researcher (SK) distilled key pieces of health information into the patient and provider versions and partnered with a film-maker/illustrator to develop the multi-media components of the ‘SMART START’ KT tool.

The integration of the following elements were based on creating an appealing KT tool that is easy to read and comprehend and relevant to its respective audiences: 1) colours: palette informed by South Asian cultural ceremonies; 2) fonts: clear, easy to read, large size; 3) interactive layout: encourages patient-physician communication, allows patients to track their own health information; 4) patient-oriented language: written in second person “you...”, short/concise/simple, assumes no prior scientific knowledge, suggestions aim to empower patients to act; 5) image

selection: different styles and textures (e.g., photos, illustrations, outlines) that resonate with diverse South Asian communities. Pictures that are closely linked to text markedly increase attention and recall to health education information (Houts et al., 2006; Morrow et al., 1998; Levie & Lentz, 1982) and culturally-reflective images facilitate comprehension more than those that are not culturally-relevant (Dowse & Ehlers, 2001); 6) size: the patient version is pocket-sized, can fit inside a small handbag for easy transport; the provider version is laminated and larger to allow for easy access in the clinic environment; 7) inclusion of audio-visual components: diverse methods can spark attention, tell a story (narrative approach), and sustain interest (Hinyard et al., 2007); 8) supplementary reminder material that concisely summaries the key points from the main booklet (See Section D, Table 1).

## **Lessons Learned**

We learned two key lessons from developing a KT tool to address a pressing public health challenge within a priority population. First, the use of principles informed by arts-based KT and illustration/design can strengthen the development of patient-centred, narrative tools. We were able to achieve this via establishing multi-sectoral and interdisciplinary partnerships that involved clinicians, patients, scientists, artists and illustrators. Developing KT tools that resonate with pregnant South Asians requires additional attention to content, wording, and imagery that intentionally embeds knowledge within cultural contexts. The use of artistic elements can help achieve those goals. Second, establishing alignment between frameworks and local evidence/needs is an important step in deciding how to illuminate knowledge for specific patient populations. We achieved this by using local need as the foundation, theoretical frameworks as a guide, and global evidence/general knowledge as supplementary components.

## **Conclusions**

In this case report, we describe the development of a KT tool that braids together 1) theoretical frameworks; and 2) empirical work that includes local need, contextual considerations, and arts-based designs as one approach to reinforcing primary care efforts for pregnant South Asians, a priority population currently facing a public health challenge. Our design approach is theoretically informed by the Knowledge-To-Action framework, the CanMEDS Family Physician competency framework, and an expanded version of the health belief model; and empirically informed by local context and arts-based KT principles. The next step of this research is to pilot test the impact of this KT tool, compile feedback, and modify with the intention of using it more widely or to address different health situations.

## TABLES

CONCEPT/COMPETENCY	DEFINTION	DESCRIPTION OF IMPLEMENTATION
<b>SECTION A: KTA FRAMEWORK (Graham et al., 2006)</b>		
Adapting knowledge to local context	Understanding the key audience(s), assessing the usefulness and appropriateness of the particular knowledge	Qualitative research was conducted to better understand the perspectives of currently/recently pregnant South Asians and their primary care practitioners
Assessing barriers and facilitators to knowledge use	Understanding the factors that can hinder and enhance knowledge uptake	Obtaining and incorporating feedback from key knowledge users with the aim of seamless integration
Selecting, tailoring, and implementing interventions	Planning and carrying out the selected intervention	Patient and provider directed educational intervention (KT Tool) was developed via interdisciplinary collaboration (e.g., end-users, researchers, creative professionals) to inform an innovative design
<b>SECTION B: HEALTH BELIEF MODEL (Rosenstock, 1974)</b>		
Perceived Threat		Visualization of risk using a percentage diagram, education around modifiable and non-modifiable risk factors
Perceived Benefits and Barriers		Engaging in practices that have the potential to prevent GDM and its complications (e.g., staying within gestational weight range, engaging in healthy active lifestyles, consuming healthy balanced diet), assistance in identifying barriers to action (via the suggestions questions/dialogue to have with healthcare providers)
Cues to action		New knowledge about GDM, promotion of GDM screening, operationalizable tips/tricks related to dietary changes, inclusion of easy and healthy recipes
<b>SECTION C: CANMEDS FRAMEWORK (Shaw et al., 2017)</b>		
Communicator	Interaction between physicians and their patients	Recommendations for positive communication with patients (starting an early dialogue, open-ended questions, building suggestions on current patient practices).
	Patient-centered communication	Samples of suggested scripts that can be used to inquire details about patient's unique experiences related to healthy active living during pregnancy.



Integration of cultural safety

Inclusion of background information pertaining to the demographic details, barriers to, and facilitators of lifestyle change among pregnant South Asian women living the Peel Region and suggested scripts to inquire further about individual experiences with their familial and community cultures

Health Advocate

Working with patients to address determinants of health that affect them and their access to needed health services or resources  
Incorporates disease prevention, health promotion, and health surveillance into interactions with individuals  
Improves clinical practice by applying a process of continuous quality improvement to disease prevention, health promotion, and health surveillance activities  
Identifies specific needs of underserved patients and populations, including reducing barriers and improving access to culturally appropriate care  
Integrates evidence into decision making in practice

Including information about supplementary public health resources that can be referred to patients

Information about GDM risk assessment and screening recommendations (based on risk)

Suggested scripts to improve upon current GDM and healthy active living dialogue

Scholar

Participates in and conducts quality-improvement activities

Summarizes and communicates the findings of relevant research and scholarly inquiry to professional and lay audiences, including patients, their families, and communities

Suggested scripts to improve doctor-patient communication around barriers to lifestyle modification and background information that can incentivize culturally-appropriate care

Demonstration of the need for early dialogue around lifestyle modification among South Asian women during pregnancy

Provider-facing toolkit in its entirety aims to improve the quality of care provided to patients

Suggested scripts to help support the translation of key research into lay terms

**SECTION D: ARTS-BASED KT AND DESIGN ELEMENTS** (Strachan et al., 2012; Centers for Disease Control and Prevention, 2009; US Department of Health and Human Services, 1994)

Language, word use, readability

Minimal use of scientific jargon and multi-syllabic words, use of active voice, and reduced sentence length

Patient-facing version uses simple language by describing clinical terminology via lay explanations. Readability was measured to be at a grade 7 level according to the Fry test (Fry., 1968): Average # of syllables per 100 words: 146; Average # of sentences per 100

Typography	Use of adequate font size font type (serif/sans-serif), typographic cues, subheadings, and capital headers	words: 7.2), speaking pace in video was slow and wording was simplified Larger size font (size 12 and higher), Serif font type, numbering to help direct readers, and use of sub-headings/capital headers to organize content
Graphics and illustrations	Use of meaningful cover graphic, simple graphics and illustrations, captions, and positioning of relevant text beside respective illustrations	Use of a “catchy” cover graphic, simple graphics and illustrations throughout both tools, simple text to accompany illustrations, and audio-visual elements to illustrate the strength of narratives
Layout, space, and paper	Matte finish, use of color/black and white, simple layout, use of visual cues, effective balance between white space, contrast, color usage	Use of uncoated matte paper to facilitate readability, culturally-relevant colour palette, simple layout with visual cues (e.g., shaded boxes to guide readers through the material), ample white space and effective contrast between text and images, size of package reflects needs of target population, interactive layout encourages patient- physician communication, allows patients to track personal information, and allows for the provision of actionable tips
Audience relevance and appropriateness	Consideration of intended audience, language that reflects audience, images culturally appropriate	Text and images were selected to be culturally relevant (to resonate either with South Asian women or their primary physicians), use of supplementary materials to summarize key points from the main content

Table 1. Process of incorporating theoretical frameworks and evidence into the design of the ‘SMART START’ KT Tool

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**Appendix 1: [Patient-Facing Tool](#)**

**Appendix 2: [Physician-Facing Tool](#)**

**CHAPTER 5:**  
**A MULTI-FACETED, MULTI-MEDIA KNOWLEDGE TRANSLATION TOOL**  
**DESIGNED FOR PREGNANT SOUTH ASIANS AND THEIR FAMILY PHYSICIANS:**  
**A MIXED METHODS PILOT EVALUATION OF AN APPROACH TO ADDRESS A**  
**PUBLIC HEALTH CHALLENGE IN A PRIORITY POPULATION**

A multi-faceted, multi-media knowledge translation tool designed for pregnant South Asians and their family physicians:  
a mixed methods pilot evaluation of an approach to address a public health challenge in a priority population

## **Introduction**

*Background:* Gestational diabetes mellitus (GDM), which is a form of dysglycemia due to elevated blood glucose levels, is diagnosed based on glucose response to an oral glucose challenge test administered typically between 24-28 weeks gestation. GDM has been associated with ample adverse health outcomes for the mother, the fetus, and the child, both prenatally and after birth (1,2). These include a higher risk of large-for-gestational-age newborns, delivery complications, and future type 2 diabetes for the mother and child (3-6). With a prevalence of 1 in 7 births and rising, GDM is becoming a global health concern, with South Asian women at higher risk than their White counterparts (7-11). GDM presents a similar concern within a Canadian context, with overall rates ranging from 3-20%, but a heightened rate of 36% among South Asian women (12, 13). Rates of GDM have been consistently climbing upwards (14), illustrating a need for the timely design of interventions that directly address this challenge, particularly for this population.

South Asians (i.e., people who originate from India, Pakistan, Sri Lanka, Nepal, and Bangladesh) are an important sub-set of the Canadian mosaic as they comprise both the largest and fastest growing visible minority group in our country (15). This number is projected to reach over 4 million by 2031, of which nearly 1 million will be women of child-bearing age (16). Evidence collected over the last 20 years suggests that cardiovascular disease (CVD) rates in South Asians are higher than other ethnic groups living in Canada (17-20), and that CVD cases in South



Asians are more severe, present at younger ages, and in some contexts have differential access to diagnostic and treatment services compared to non-South Asians (21-23). Among South Asian women, the reasons for increased risk have been attributed to increased pre-pregnancy weight, advanced maternal age, family history of diabetes, excess gestational weight gain, and low diet quality (12, 24-26). Previous work has also demonstrated that high-quality, culturally-relevant, evidence-based GDM resources are needed (27-30). To address some of these gaps, we designed a theory-informed, evidence-based, multi-media Knowledge Translation (KT) tool ('SMART START') to improve knowledge, attitudes, practices, and confidence among pregnant South Asian women and their primary care practitioners in regard to GDM lifestyle counselling ().

*Objectives:* The aim of this pilot evaluation was to use a mixed methods approach to evaluate the feasibility and acceptability of the SMART START KT tool. Secondary outcomes include the impact as measured by change in knowledge, attitudes, practices, and confidence.

## **Methods**

*Study design:* We conducted a pilot mixed methods parallel convergent evaluation comparing women and family physicians receiving the 'SMART START' KT tool ("intervention group") to those receiving the standard care College of Family Physicians Prenatal Health resource ("control group"). This pilot feasibility trial was used to understand a complex process that occurs in a natural settings by the way of multiple data sources (31, 32). The design, theory-informed process, and development of the KT tool is described elsewhere (33). Our primary outcome was the assessment of feasibility (as described by recruitment, retention, intervention acceptability, and overall experiences) and our secondary outcomes included an assessment of change in knowledge, attitudes, practices (KAP) and confidence. For this pilot evaluation, we aimed to recruit two family

practices (one to be randomized to the intervention group and the other to the control group) and 10 pregnant women from each practice, for a total sample size of 20 women.

*The intervention:* The patient-facing version consisted of three unique but synergistic components: 1) a digital narrative about GDM (short introductory video); 2) a pocket-size booklet containing information about GDM risk factors, maternal and child health impacts of GDM, guiding questions for patients to explore with their family doctors, and options for tracking weight goals; 3) a reminder magnet summarizing key actionable lifestyle modification tips. The family physician-facing tool contained scripts and evidence-based information to counsel South Asian patients on GDM prevention during pregnancy.

*Study population:* Two local family practice clinics in the Peel Region, Ontario, Canada took part in this study. The Peel Region consists of the municipalities of Brampton, Caledon, and Mississauga. It is home to 1.5 million residents and with 50.8% identifying as South Asian, it is the largest community of South Asians in Ontario (34). Eligibility criteria for women included being <12 weeks gestation with a live singleton pregnancy, no previous clinical diagnosis of type 1 or 2 diabetes, and an elementary level proficiency in English. Patients were excluded from this study if they were pregnant with multiples, were not planning to attend a prenatal visit with their family doctor, or were receiving specialized dietary counselling due to a previous diagnosis of diabetes.

*Recruitment and study conduct:* Approval from the Hamilton Integrated Research Ethics Board was obtained prior to the commencement of this study (Project #: 5863). A double-pronged recruitment strategy was deployed. First, researchers SK and SSA sent out 45 personalized faxes

to family doctors in the Peel Region to recruit interested practices. Second, SK contacted high volume clinics from our list of previously established partnerships. Once we recruited our first two clinics, SK held a meeting with the interested family physician to review the study protocol and complete the informed consent process. Therein, the family physician completed the baseline assessment (demographic questions, quantitative survey assessing KAP/confidence, and an open-ended interview assessing clinic procedures/KAP/confidence). Using a public flip of a coin, both clinics were randomized to either the intervention or control group. After randomization, a package containing: 1) referral forms; and 2) 10 colour copies of the respective resource packages were delivered to the clinic reception. Family physicians proceeded to introduce the study to consecutive women as they presented for potential pregnancy confirmation. If patients were interested in the study, a consent to contact form was completed and faxed to the research office for processing. On the same day the fax was received, SK contacted the referral via cellphone. First a text message was sent to remind the participant of the study and to request an appointment time. Once confirmed, SK called the participant to review the study and complete the informed consent and baseline assessments (demographic questions, quantitative survey assessing KAP/confidence, and an open-ended interview assessing clinic procedures/KAP/confidence). Initially planned face-to-face visits at the family practice transitioned to phone calls, text/Whatsapp messages, and email correspondence due to the limitations imposed by the COVID-19 pandemic. The RedCap link to the informed consent form, electronic signature option, demographic questions, and quantitative survey was administered via email. All baseline open-ended interviews were conducted via telephone. After each enrollment, the full name of the participant and date of baseline assessment was communicated to the family physician directly. At their next visit (major prenatal assessment), the intervention or control resource and corresponding “Healthy Active Living” dialogue was

administered. Each participant also received a \$10 gift card for their involvement in the study. When the participant entered their third trimester (approximately between 24-30 weeks gestation), the final study visit was administered. Similar to the baseline assessment, the RedCap link to the quantitative survey was shared via email and the open-ended interview was conducted via telephone. After all participants completed their exit interview, the clinic physicians were contacted for their final study visit. The RedCap link to the quantitative survey was shared with them via email and the open-ended interview was conducted via telephone. All interviews were audio-recorded and transcribed verbatim. All quantitative data was stored on the password protected RedCap database and all interview transcripts were de-identified and stored on a password protected server.

*Data collection:* For pregnant participants, we collected demographic information on date of birth, practitioners to be included in prenatal care, languages spoken, religion, education level, current employment status, previous pregnancies, current living status, and number of years living in Canada. For family physicians, we collected demographic information on years in practice post-residency (total # years), languages spoken with patients, % patient population seen prenatally, % pregnant women seen during the first trimester, % South Asian pregnant patients, and time spent counselling on GDM.

Quantitative strand: We developed patient-facing questions to assess knowledge, attitudes, and practices using a combination of 5-point Likert scales and multiple-choice questions. With a total maximum score of 16, knowledge questions focused on GDM risk factors, impact of GDM on the unborn baby, weight gain recommendations, physical activity guidelines, and diet. To assess

attitudes (total score of 15), we inquired about their concern around GDM, willingness to make change, and willingness to engage with their family physicians on this topic. To assess current practices, we developed questions around behaviours related to healthy active living such as dietary choices, frequency of physical activity, choices around tracking weight gain, completion of risk assessments, and screening decisions. Physician-facing questions also focused on knowledge, attitudes, and practices using a 5-point Likert scale. With a maximum score of 5, the knowledge assessment focused on a self-reflective knowledge score on counselling pregnant South Asian women on GDM prevention. With a maximum score of 5, the attitude assessment was a self-reflective score of the importance of counselling South Asian women on GDM prevention. With a maximum score of 5, the practice assessment was a self-reflective score on how well GDM counselling is performed. Finally, we assessed patient-level confidence in continuing with or making adjustments to healthy active living lifestyle practices (total score of 20) and provider-level confidence in GDM prevention counselling (total score of 65). All domains were assessed for face validity (via expert review) prior to use and were designed to take approximately 15 minutes to complete in full.

**Qualitative strand:** We developed a semi-structured interview guide with brief, open-ended questions to better understand knowledge, attitudes, current practices, and confidence (at baseline and end-of-study). Questions inquired about familiarity with GDM, lifestyle change (including barriers and facilitators), diet/physical activity, preferences around knowledge exchange, and additionally at the exit interview only, general attitudes toward the KT tool in terms of content, information, and layout.

**Data analysis:** According to a convergent parallel design, both quantitative and qualitative strands were conducted in tandem. Demographic variables, study recruitment, retention,

acceptability, knowledge, attitude, practice, and confidence scores were collated using descriptive statistics. Variables were also exploratorily compared between the intervention group and the control group using a Mann Whitney U test. All quantitative data were analyzed using R V4.0.3. Qualitative data were transcribed verbatim and analyzed using a qualitative description (thematic analysis) approach (35, 36). A staged coding process was employed. This approach allowed us to explore relevant themes from participant interviews by systematically identifying patterns and logically organizing qualitative data into broader common and representative insights. This logical organization of data into broader recurring themes (e.g. data reduction) helps to better explain aspects of the phenomena under examination (i.e., prenatal GDM counselling using health resources). In general, our analytic strategy of constant comparison included the following stages: 1) code-development as the basic analytic unit capturing important aspects of data, and 2) the derivation of broader themes that illustrate a coherent picture of collected data (35, 36). After the collection of qualitative and quantitative data, the results were integrated into a mixed methods analysis (37) so that inferences within both strands and meta-inferences across both strands could be made (38). Our integration approach involved the direct comparison of qualitative and quantitative findings and making assessments about congruency and discrepancies using a circular joint display (37).

## **Findings:**

Recruitment: Between January and July 2020, we enrolled 20 pregnant women into this study (10 women from each of the two clinics). On average, this was 3 women/month. Despite the challenges coupled with limited in-person clinic visits since the onset of the COVID-19 pandemic, recruitment was completed between March and July 2020 (See Figure 1).

We enrolled consecutive women into the study for almost each of the seven months of active recruitment. For two of the included months, we had one additional pregnant woman screened per month who did not enroll into the study (Figure 2). The reasons for deciding not to enroll were due to: 1) immediate transfer of care to a midwife; and 2) competing priorities stemming from pandemic regulations.

Demographic details: 20 South Asian pregnant women were included in study, 10 in each group. The mean age was 31.7 and 29.7 in the control and intervention groups respectively and all participants were planning to include their family physician in their prenatal care. In addition to English, diverse South Asian languages were spoken across both groups—Urdu, Hindi, Punjabi, Kannada, Tamil, Dhari, and Persian. Religious affiliations ranged from Hindu, Sikh, Muslim, and multiple (Hindu and Sikh), with more diversity in the control group compared to the intervention. Most participants were employed full-time, had been pregnant before, and were born outside Canada (See Table 1 for more details). There was some disparity between the number of years participants had spent in Canada, with the mean number of years being 7 and 13 for the control group and intervention group, respectively. The providers had 12 years of experience each in independent practice, spoke a variety of South Asian languages, had prenatal patient population of 20-25%, saw 60-80% South Asians, and currently spent between 5-6 minutes counselling their prenatal patients on gestational diabetes prevention (See Table 2 for more details).

Quantitative Strand: We found good acceptability in the intervention and with strong partnerships from clinic physicians, found feasibility in recruitment. We were able to screen and enroll on average 3 pregnant South Asian patients per month with two centers. Two pregnant participants were unenrolled due to miscarriage. All others completed all components of the study

(See Figure 3 for the CONSORT Flowchart). A high level of acceptability was received from patients and practitioners for timing, content, format, language, and interest of the interventions delivered. The median score was 18 (total 21), with 50% of pregnant women ranking their acceptability scores at >87%. The median score for the family physicians was 28 (total 31), with both ranking their acceptability at >90%.

Secondary outcomes: Median knowledge, practice, and confidence scores improved in the patient and provider intervention groups; attitudes scores, which were demonstrated to be high at baseline remained consistent throughout the evaluation period. Mann Whitney U tests did not indicate significance between the groups for any of the categories.

Gaps in patient knowledge and practices were present in the following areas: GDM risk factors, impact of GDM on the unborn baby, weight gain recommendations, diet, physical activity practices, and tracking of weight gain.

Qualitative Strand: Our qualitative description illustrates the distinct and shared perspectives of primary care physicians and their pregnant South Asian patients as it pertains to healthy active living counselling. We conceptualize these major themes using the schematic of a stethoscope, where the headpiece represents the physician's perspectives; the chest piece represents pregnant South Asians perspectives; and the connecting cord represents shared perspectives and mutual understandings.

*Head piece:* Within this significant theme, we understand the primary counselling perspectives of family physicians as it relates to healthy active living topics and patient-centered care. Practitioners engage in an open-ended counselling and use simple hand-drawn visuals (e.g., to illustrate portion sizes) to increase receptiveness. They begin the prenatal visit with a brief



screening around family history of diabetes and previous pregnancies (with an emphasis on previous diagnoses of gestational diabetes and newborn birth weights). Guided by goals to motivate, remind, and promote, physicians favoured using a personalized approach that focused on weight management. Physicians acknowledged that these interactions existed within a cultural mix of different lifestyles and food preferences. For example, one physician said, *“So it’s kind of this big cultural mix that you have to think about and advise them you know? There are challenges with each and every scenario. It’s just that every time they come and they are persistent and reminding them to keep going.”* Both physicians were approaching this study with over 12 years of family medicine expertise each but were open to learning about and incorporating new patient-facing approaches and resources to enhance their prenatal counselling efforts. Both physicians appreciated the provision of a toolkit for their patients, with the intervention physician stating that the toolkit is useful for all pregnant South Asians, regardless of whether they had previous pregnancies or a previous gestational diabetes diagnosis because most could *“benefit from a refresher.”*

*Chest piece:* Within this salient theme, we would like to illustrate three key sub-themes that relate to pregnant South Asians perspectives on healthy active living counselling: 1) personal perceptions of healthy active living during pregnancy; 2) experiences and preferences with gathering and searching for information; 3) key preventative behaviours. Regardless of allocated group, pregnant South Asians expressed that healthy lifestyles and the associated preventive practices was an important topic to discuss and gain more knowledge about. Food and nutrition concerns were prioritized over physical activity concerns. There were concerns about how weight gain impacts labour and delivery and some expressed worry about their downstream type 2

diabetes risk (especially if there was a family history of diabetes). Many equated physical activity with “moving around and staying active” rather than with structured physical activity, described “sugar” as breads, rice, and sweets with their intake being limited, importance of partaking in GDM screening, and a gap in knowledge around the impact of GDM on the unborn baby and risk factors in addition to family history.

Compared to women with previous children, primiparous patients prioritized searching for and engaging with prenatal information. Healthcare providers, mobile healthcare applications, and peers were important sources of information; searching via Google was not a preferred route because it can lead to unnecessary fears and women were cognizant that every pregnancy is different and not everything may apply to them directly. Women preferred personalized guidance (especially in regard to weight gain). Those who received the intervention expressed that it was a great ‘springboard’ to learning more. They wanted more guidance around simple exercises for better weight gain control, step-by-step videos on food preparation, and other how aspects of healthy active living can help prevent other pregnancy complications (e.g., pre-eclampsia and bacterial/viral infections). The paper format was preferred by most (some preferred an app) because looking at screens made them more nauseous. Some wanted both in case they misplaced the physical copy.

All participants stated that they would recommend the intervention toolkit to their family and friends because of the quality of information, style, colour choice, and eye-catching visuals (e.g., pictures allowed people to connect to the material). Many could recall the contents of the intervention toolkit, which was not the case for the control toolkit. Those who received the control

toolkit indicated that they would also share it with family and friends but for reasons related to the information enclosed.

With regard to prioritizing key healthy active living preventative practices, participants described that they aim to actively avoid bread, “too much rice”, fruits, and processed sugars and prioritize balanced meals (“a colourful plate”). They also stressed the importance of portion control rather than eliminating certain foods (e.g., eating one square of chocolate from a bar because it is tough to “cut everything out”). Challenges included cravings (especially for sweets/sugars/chocolates), nausea, and the limited confidence in cooking/food preparation skills especially in regard with traditional South Asian foods. Many also expressed that they need more than a recipe to confidently make South Asian meals (e.g., step-by-step video with detailed explanations). Interestingly, although all participants who received the intervention toolkit praised the recipes, they did not actually make any of the dishes. They described that they did not have the time to make them, or that they are not the primary food preparers in their households—it is either their mother, mother-in-law, or they order home cooked meals from a community “Aunty” or “Tiffin service” (homecooked takeout).

*Connecting cord:* Shared perspectives and mutual understandings (overarching ideas) include two sub-themes: 1) increasing receptiveness of healthy active living counselling by “meeting people where they are” and 2) opportunities for new interventions and resources.

In regard to “meeting people where they are,” it was important to set the ground for healthy active living counselling by getting to know the patient (including family arrangement), building a trusting relationship, starting simple, tailoring guidance, using identifiable stories/explanations, being able to use South Asian languages to better connect (if needed), and the maximizing on the

benefits from a family-centric approach to healthy active living. In regard to new opportunities and resources to supplement current healthy active living counselling approaches, the following areas were suggested: the provision of specialized content for patients with obesity who got pregnant while in the midst of weight reduction, more information about community resources (e.g., especially for newer South Asian immigrants to the Peel Region), more education around the importance of weight control, greater need to provide encouragement and motivation around maintaining physical activity, the need for health communication to be provided in digestible components (e.g., by trimester), inclusion of other related concerns such as isolation/mental wellbeing due to the pandemic/stay-at-home orders, and lastly, it was noted that because more health conscious patients are coming in for pre-conception physicals, this could allow for additional feasible avenues for health communication.

**Convergent Analysis and Integration:** Joint displays integrate the qualitative and quantitative data to help draw out new synergies beyond the separate analyses. After several iterations and crystallizations, we developed the final circular joint display to illustrate the converging and diverging components of both the qualitative and quantitative meta-interferences. This joint display was a fusion between side-by-side and comparing results display (38). We developed concentric rings around the primary and secondary outcomes of the evaluation, followed by the quantitative survey data, qualitative themes, and finally with indications of convergence and divergence. To illustrate and describe this merging of data, we used words such as confirmation, discordance, and expansion to indicate similarities, discrepancies, and a need for further exploration between the data strands, respectively (39). Integration illustrates that the primary outcomes of feasibility and acceptability have convergence in terms of qualitative and quantitative data. The knowledge and confidence domains exhibit features of expansion (a need for further

exploration due to quantitative data demonstrating positive change and qualitative data illustrating additional recommendations); practices indicate convergence (positive qualitative and quantitative data); and attitudes display features of discordance (negative change in quantitative data and positive change in qualitative data). See figure 4 for the joint display and all the corresponding details.

### **Discussion:**

The primary objective of this pilot study was to evaluate the feasibility and acceptability of a prenatal KT tool tailored for South Asians. We were able to demonstrate feasibility and acceptability in design, content, format, language, interest, and timing of intervention delivery among pregnant South Asians and their family physicians. Successful components of this pilot was determined to be recruitment completed within 12 months (20 patients over 12 months, which equates to 1-2 pregnant patients recruited per month) with >80% (16 pregnant patients) retention and acceptability. As we were able to achieve these two key components, it is predicted that a fully powered trial to assess change in knowledge, attitudes, practices, and confidence in this population will demonstrate achievable recruitment and retention goals with minimal modifications.

Because pilot studies are small-scale, preliminary studies that aim to investigate crucial components of a larger randomized control trial, they provide insight into process, resources, and management (40). Sample size discussion should prioritize the recruitment of a representative sample and for the generation of enough information to make assessments about feasibility components; they are not powered to detect meaningful differences in clinical endpoints (40). The pairing of a) a sample size of 20 pregnant women and two family physicians across two different

medical clinics with b) the use of a mixed methods approach, we were able to generate the necessary information to draw rich conclusions about feasibility and intervention acceptability. Although the evaluation of knowledge, attitudes, practices, and confidence were exploratory, it provided some useful insights into how the KT tool can be further improved to meet the needs of this population.

There was deep interest for the provision of resources and information about healthy active lifestyles, GDM, and other related prenatal concerns. Other recent studies have also demonstrated similar interests for KT tools in prenatal settings as they relate to gestational weight gain (e.g., 41). Arts-based KT tools, such as the SMART START tool, show promise. Artistic representations express various qualities and as such, foreseeably impact viewers in distinct ways (42). For example, visual representations may foster more emotive responses when compared with text only, which elude more rational responses (43); music provokes imagination and fosters meaning-making (44); and theatre promotes engagement and helps crystallize abstract concepts (45). Due to these differences, the selection of arts-based approaches should be informed by an understanding of the form, population, context, location of use, desired outcomes (e.g., improving knowledge, attitude change), the extent of message distillation, and efforts to co-create products with communities of interest (46). When designing the SMART START tool, we used multi-media and digital features (specifically the choice of music, use of video, building in a narrative approach, supplementary visuals, language selection) to help balance comprehensiveness with simple explanations that better resonate with our priority population. We also designed the tools with coordination and consistency across the multi-media formats and the meaningful use of visuals to enhance text. In general, tool content and style were well accepted, however, some modifications

are required before proceeding to a full trial. These include revisions to the KT tool to reflect patient and provider suggestions: the addition of step-by-step prenatal physical activity videos, step-by-step food preparation videos, and links to local community resources. Lastly, in terms of management, via the reflection of the diverse languages (in addition to English) that are spoken by the sample, it is recommended that the tools, surveys, and interviews be developed in other South Asian languages.

**Conclusion:**

We describe the evaluation process of a theory-informed, evidence-based, multi-media KT tool designed to educate pregnant South Asians and their family physicians on the topic of GDM. The pilot evaluation demonstrated feasibility and acceptability in process. In terms of management, we plan to develop the tools, surveys, and interviews in other South Asian languages; in terms of resources, we also plan to address minor modifications to tool content prior to advancement to a full trial.

## FIGURES

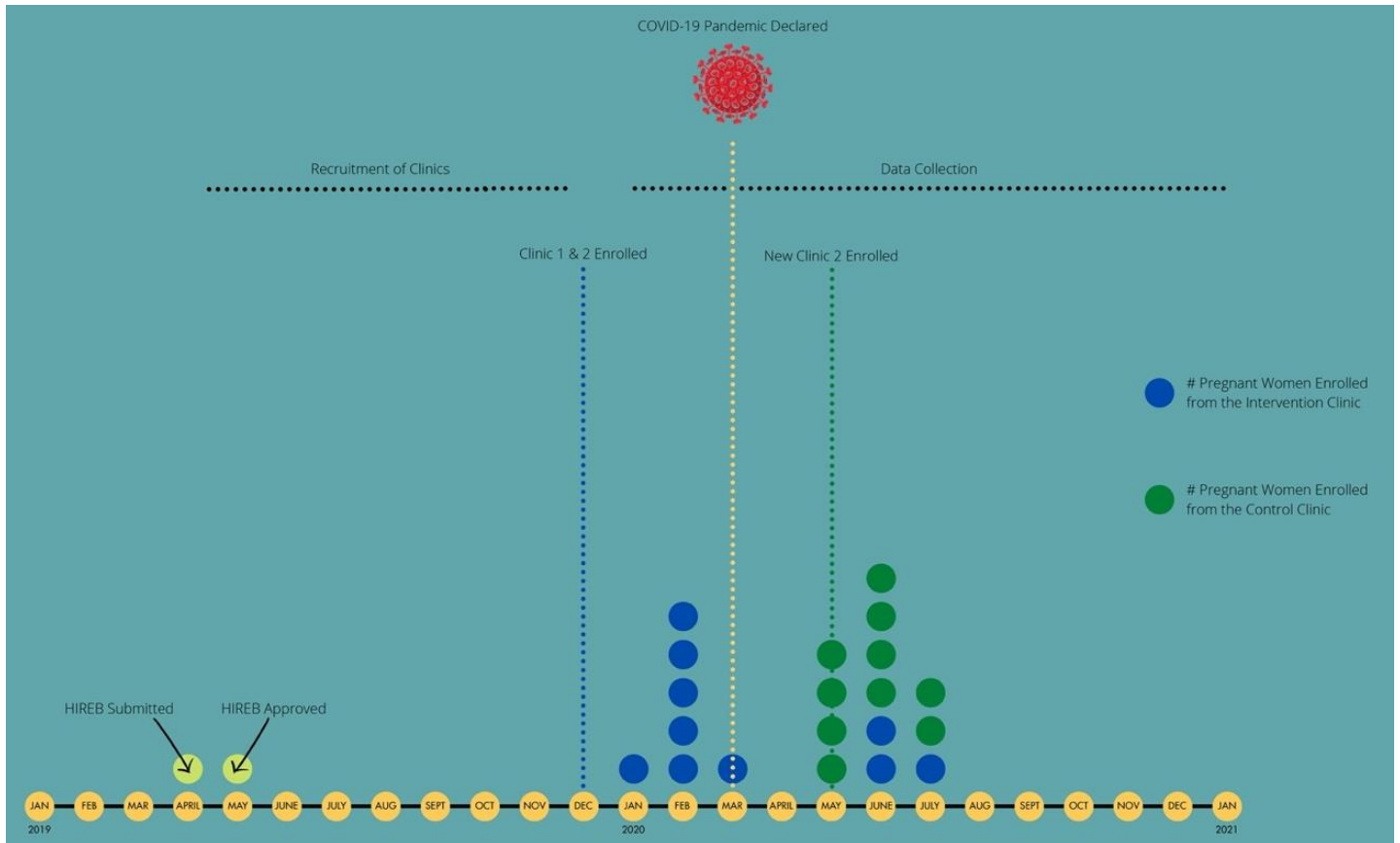


Figure 1. Study process diagram highlighting study recruitment by site (control and intervention clinics) between January 2019 and January 2021.



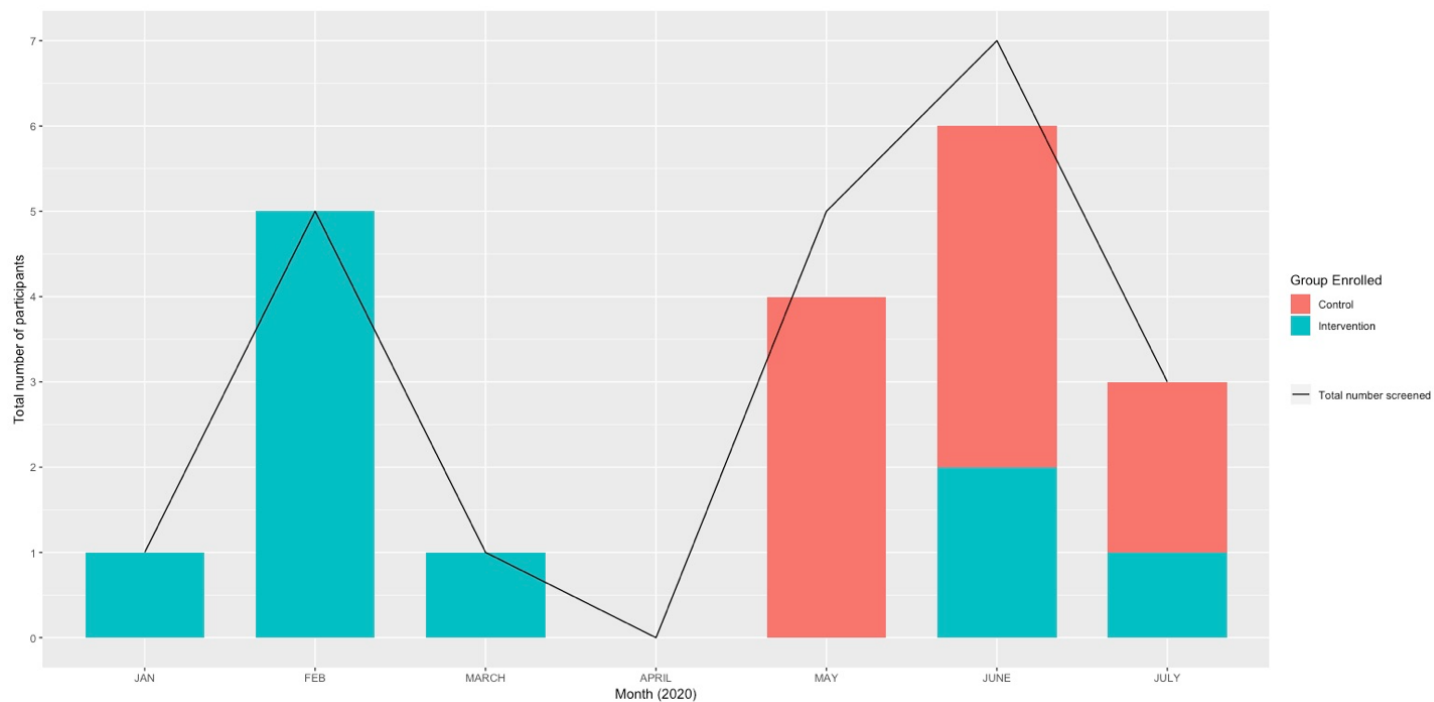


Figure 2. Recruitment process (screened and enrolled) into the study between January and July 2020.

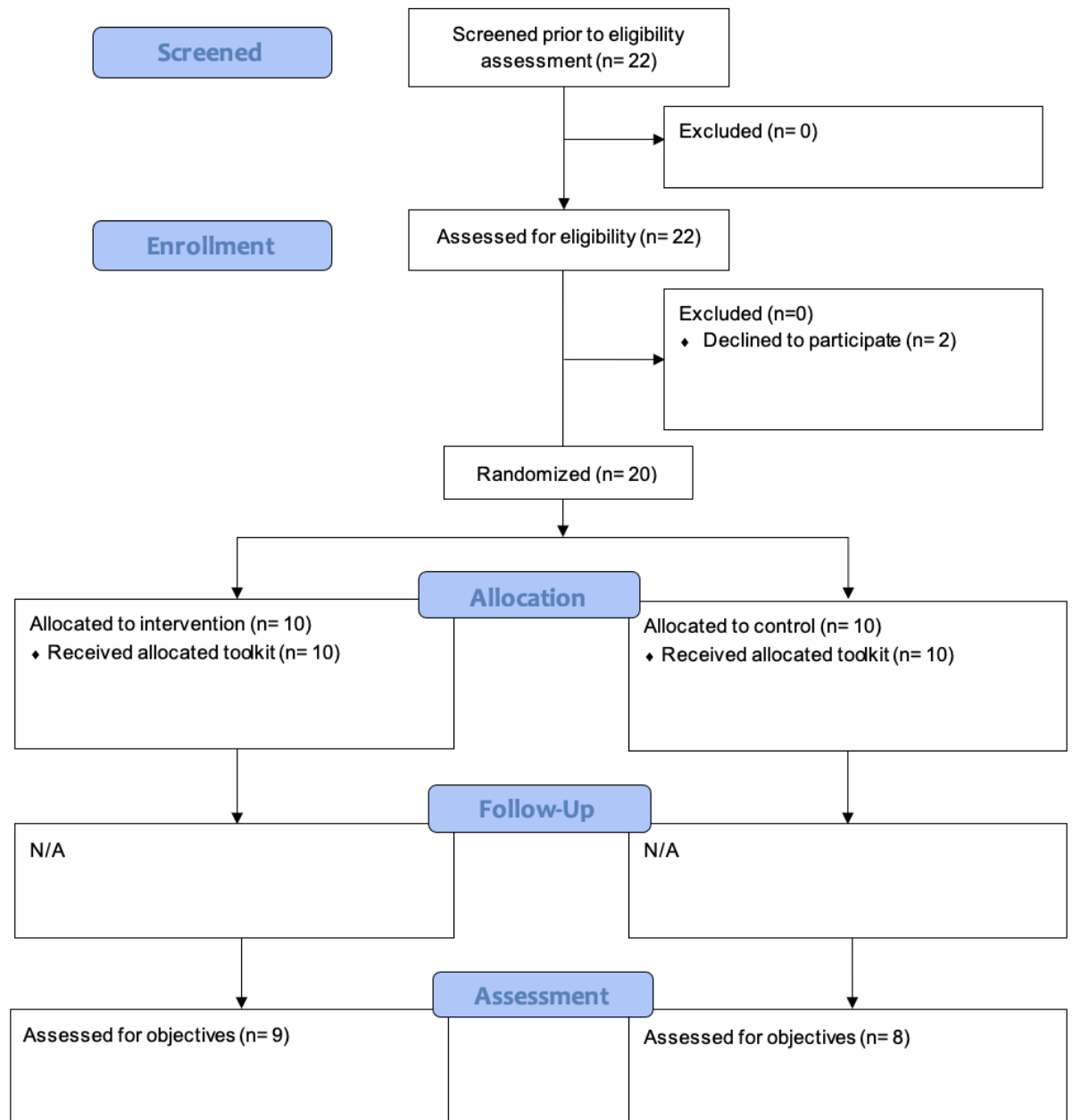


Figure 3. CONSORT flowchart

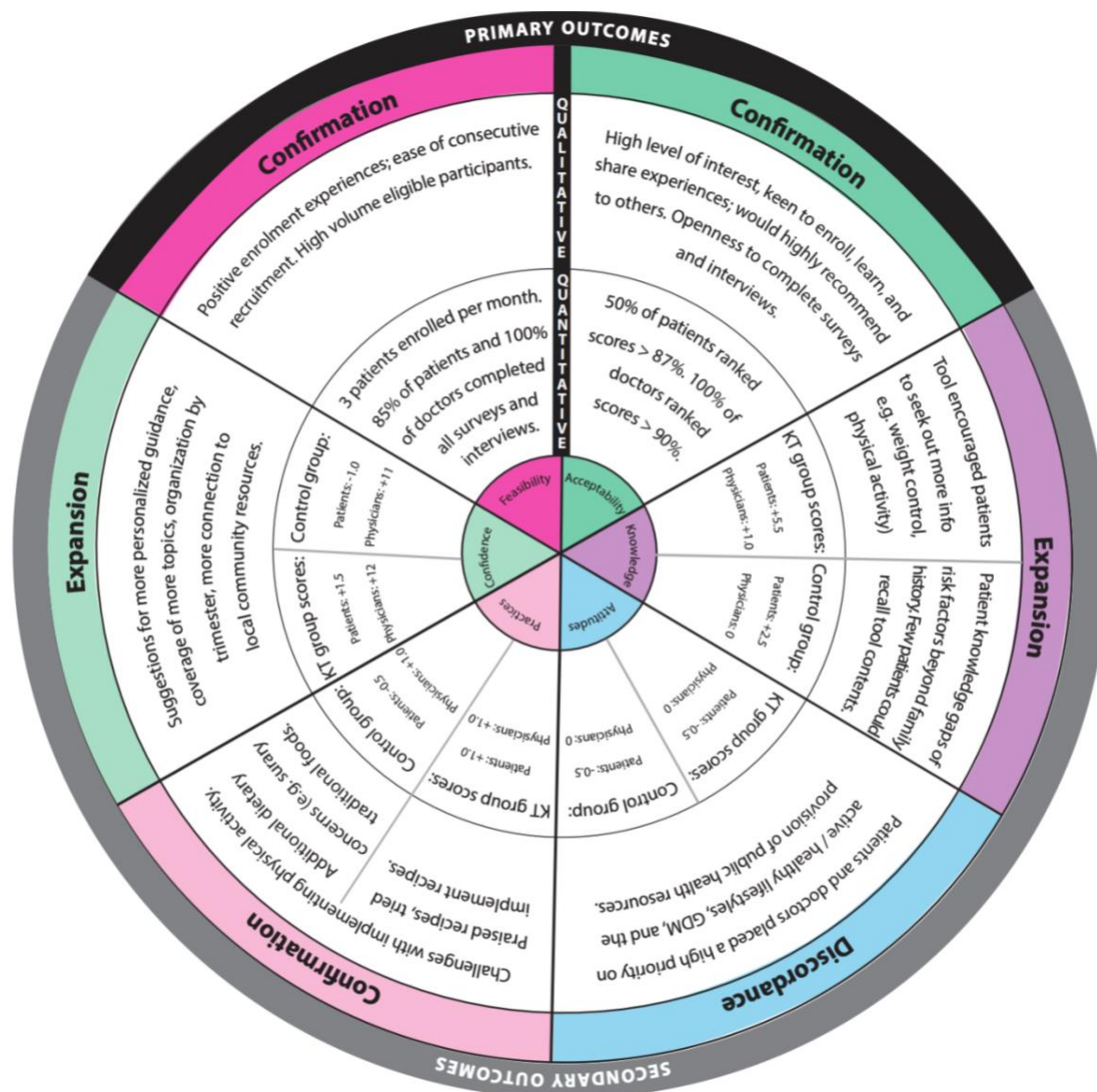


Figure 4. Joint display. The centre circle outlines primary and secondary outcomes. The first circle outside of the centre describes the quantitative summaries as per each outcome and per group. The next circle describes qualitative findings per group. The third circle indicates the level of convergence and divergence and the outermost circle re-iterates which analyses were primary and secondary.

## TABLES

	Control (n=10)	Intervention (n=10)
Age (mean (SD))	31.70 (3.16)	29.70 (4.95)
<b>Practitioners to be included in prenatal care</b>		
Family physician	10 (100.0)	10 (10.0)
OB/GYN	5 (50.0)	7 (70.0)
Midwife	3 (30.0)	2 (20.0)
Other	1 (10.0)	0 (0.0)
<b>Languages spoken (%)</b>		
English	10 (100.0)	10 (100.0)
Urdu	3 (33.3)	9 (90.0)
Hindi	2 (22.2)	2 (20.0)
Punjabi	3 (33.3)	1 (10.0)
Kannada	1 (11.1)	0 (0.0)
Tamil	2 (22.2)	0 (0.0)
Dari	0 (0.0)	1 (10.0)
Persian	0 (0.0)	1 (10.0)
<b>Religion (%)</b>		
Hindu	4 (40.0)	0 (0.0)
Hindu & Sikh	1 (10.0)	0 (0.0)
Muslim	3 (30.0)	10 (100.0)
Sikh	2 (20.0)	0 (0.0)
<b>Highest level of Education Attained (%)</b>		
Bachelors	4 (40.0)	4 (40.0)
College diploma	2 (20.0)	5 (50.0)
Masters	3 (30.0)	1 (10.0)
Professional degree (e.g., MD)	1 (10.0)	0 (0.0)
<b>Current Employment Status (%)</b>		
Employed full-time	5 (50.0)	4 (10.0)
Employed part-time	0 (0.0)	1 (10.0)
Home-maker	4 (40.0)	5 (50.0)
Unemployed	1 (10.0)	0 (0.0)
# of Total Pregnancies (mean (SD))	2.20 (1.14)	1.70 (1.06)
# Previous births (mean (SD))	0.80 (0.63)	0.50 (0.97)
<b>Current Living situation (%)</b>		
Live with parents only	0 (0.0)	2 (20.0)
Live with parents and siblings only	0 (0.0)	1 (10.0)
Live with spouse only	4 (40.0)	1 (10.0)
Live with spouse and other children only	5 (50.0)	3 (30.0)

<b>Live with spouse and in-laws only</b>	1 (10.0)	2 (20.0)
<b>Live with spouse, parents, and other children</b>	0 (0.0)	1 (10.0)
<b>Birth location in Canada</b>	1 (10.0)	1 (10.0)
<b># Years in Canada (mean (SD))</b>	7.11 (9.02)	13.70 (10.10)

Table 1. Demographic details of enrolled pregnant women participants

	<b>Control (n=1)</b>	<b>Intervention (n=1)</b>
<b>Years in practice post-residency (total # years)</b>	12	12
<b>Languages spoken with patients</b>		
<b>English</b>	Yes	Yes
<b>Urdu</b>	Yes	Yes
<b>Hindi</b>	Yes	Yes
<b>Punjabi</b>	Yes	No
<b>Patient population seen prenatally (%)</b>	20	25
<b>Pregnant women seen during the first trimester (%)</b>	90	95
<b>Prenatal patient population of South Asian descent (%)</b>	60	80
<b>Time spent counselling on GDM (mins)</b>	6	5
<b>Difference in time spent counselling South Asian patients vs. other ethnicities on GDM</b>	Yes, more time spent	No difference

Table 2. Demographic details of enrolled physician participants

	<b>Median Knowledge Score (/16)</b>	<b>Median Attitudes Score (/15)</b>	<b>Median Practices Score (/5)</b>	<b>Median Confidence Scores (/20)</b>
<b>Intervention (n=8)</b>				
Pre-test	7.0	14	2.5	13.0
Post-test	12.5	13.5	3.5	14.5
Change	5.5	-0.5	1.0	1.5
<b>Control (n=6)</b>				
Pre-test	3.0	13.5	1.5	13.0
Post-test	5.5	13	1.0	12.0
Change	2.5	-0.5	-0.5	-1.0

Table 3. Patient scores (pre and post test) between intervention and control groups across the domains of knowledge, attitudes, practices, and confidence

	<b>Knowledge Score (/5)</b>	<b>Attitudes Score (/5)</b>	<b>Practices Score (/5)</b>	<b>Confidence Scores (/65)</b>
Intervention (n=1)				
Pre-test	3	5	3	45
Post-test	4	5	4	57
Change	1	0	1	12
Control (n=1)				
Pre-test	4	5	4	46
Post-test	4	5	5	57
Change	0	0	1	11

Table 4. Practitioner scores (pre and post test) between intervention and control groups across the domains of knowledge, attitudes, practices, and confidence



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## **CHAPTER 6: CONCLUSION OF THE THESIS**

## **PART A: Summary of Findings**

In this dissertation, I present an exploration of how a theory-informed, evidence-based, multi-media KT tool can be designed and evaluated to address an immediate public health challenge in a priority population. The first stage of this work, which is nested within all the other components includes identifying the challenge, determining knowledge gaps, creating avenues to address gaps, identifying/reviewing/selecting knowledge (i.e., birth cohort results, systematic reviews, local qualitative assessments to better understand population perspectives). The second level of this work included pairing the evidence with theoretical frameworks (e.g., Knowledge-to-action cycle, modified health belief model, CanMeds Framework) to develop a series of multi-media KT tools (patient-facing and physician-facing). The third level of this work was to evaluate the tools in real-world settings (family practices in the Peel region) to better understand feasibility (recruitment, retention), acceptability, and interest; and explore knowledge, attitudes, practices, and confidence. The overall purpose of the evaluation process is to assess barriers/facilitators to knowledge use, tailor/implement interventions, monitor use, and evaluate key outcomes. Finally, the last level was to develop a community-facing film that highlights the overall results of this project, as an effort toward end-of-study KT and to strengthen efforts to sustain knowledge use. To achieve this, I collaborated with a South Asian illustrator (Soumbal Qureshi) and film-maker (Bhavna Samtani) to develop the short film. To emphasize how all of these components are nested within each other, I have developed the following schematic (see below).

## FIGURES

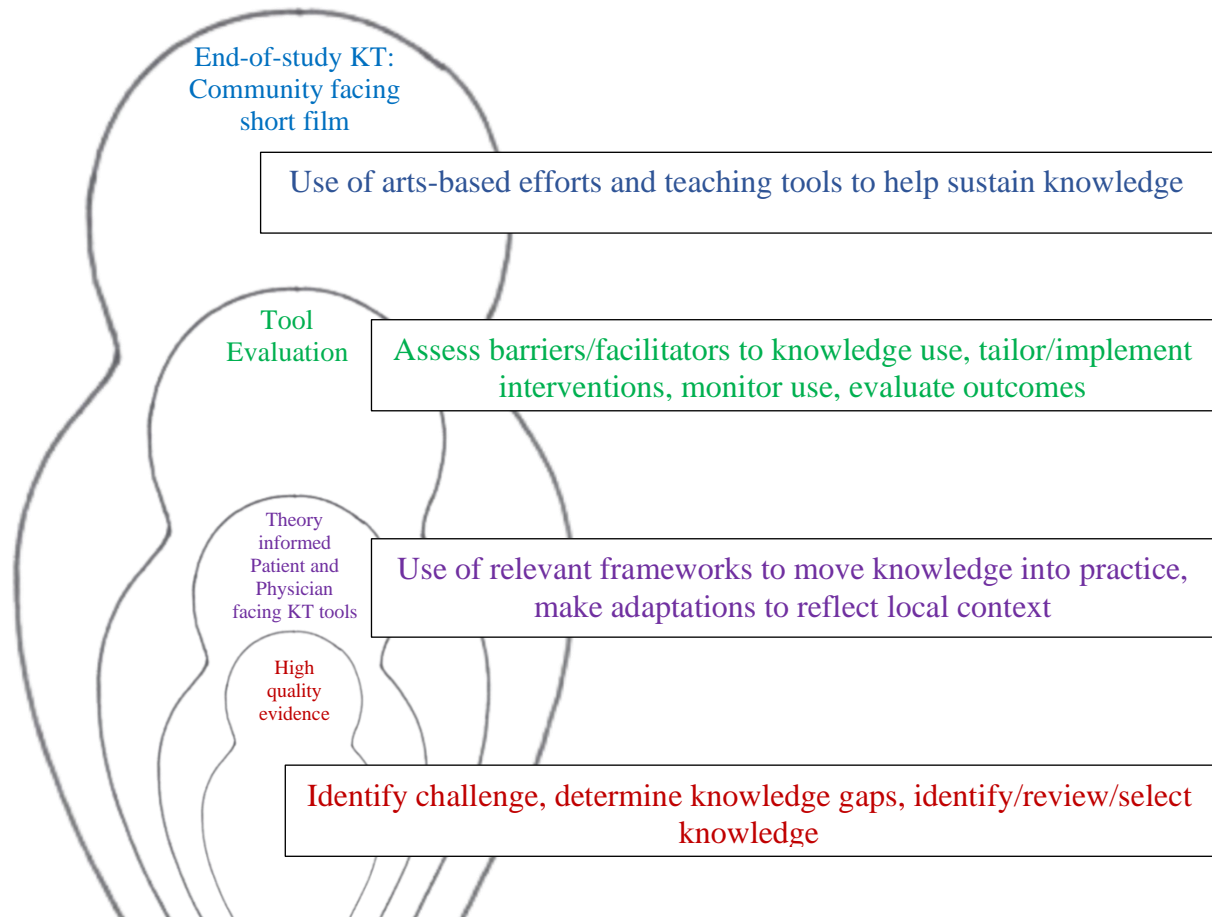


Figure 1. Nested view of evidence, tools, evaluation, and end-of-study KT project

## **PART B: Obstacles Overcome, Lessons Learned, and Future Directions**

### **1) The backdrop**

The last project within this dissertation was largely conducted and written during the COVID-19 pandemic and upon the backdrop of the many health inequities that were unveiled and reiterated over the 2020/2021 year. Many of these inequities are interweaved and interconnected with the lives of South Asian communities, and disproportionately impacted those residing in the Peel region. The higher infectivity and mortality from COVID-19 among South Asians suggest that unique socio-cultural factors including multigenerational households or occupational factors (e.g., essential work) may explain these ethnic differences.

The impact of lockdowns and public health restrictions contributed to three primary areas where I had to make pivots on my research protocol. First, we had originally planned that I would be present at the clinic locations to complete the baseline assessments of each recruited participant. Because of public health protocols, not only was I not able to attend clinic in-person, but the family physicians were also shifting many of their appointments to virtual platforms (either phone calls or virtual appointments). This resulted in the shift to a slightly modified process (see Figure 1): once the physician met with a patient to confirm a pregnancy, they would explain the study and seek interest. If the patient was interested, they would complete a “consent to contact” form with details about the participant’s name and preferred method of contact (cell phone, home phone, or email) (A). The physician would then fax the form to the central research office (McMaster University, MDCL 3200) where I would be able to securely access the document. I would then contact the participant and set up a time to complete their virtual baseline interview, which



included the consent process, quantitative survey, and qualitative interview (30min total) (B). Written and verbal consent was obtained electronically prior to moving forward to the questions. After the completion of the baseline, the doctor would be informed that the participant was enrolled into the study and would provide the counselling/resource to the patient at their major prenatal visit (C). I would then have one virtual check-point with each participant (typically done over text as per the participant's preference) during the second trimester (D) before scheduling a virtual end-of-study interview during the beginning of their third trimester (E).

Second, in some cases, participants received their counselling virtually and then were either mailed a copy of the tool, came to pick it up at reception after the virtual appointment, or were sent an electronic copy. For all the participants in the intervention arm of the study, the first component of the tool (the clinic video) was transitioned into the Redcap survey, where they could watch the video immediately after completing the baseline survey/interview. The tracking of written consents were also transitioned to electronic formats and embedded into the Redcap survey. After review, participants were able to electronically sign off directly on their devices and could also download a PDF copy of the consent form to keep for their records.

Third, from these experiences, I learned the importance of pairing ethical conduct with agility and flexibility, especially during the design phase of research studies. Building in patient-centered approaches to study protocols can be especially helpful in aligning those goals. For example, coming to the table with the understanding that different participants may have different needs (e.g., some may wish to meet in person while others may prefer alternative approaches) and building in those elements during the first ethics application and help remove time-related delays

around re-submissions and amendments later in the process. Furthermore, I also had one participant who preferred to type out their answers to the interview questions rather than participating in a traditional oral conversation. This meant I would send them the questions, they would respond, and then I would follow-up with any additional questions. Other examples of patient-centered approaches to data collection that were used in this work include 1) tracking and returning calls when requested; 2) responding promptly to questions/concerns; 3) scheduling interviews around the participant's needs (which meant being flexible during evenings and weekends); 4) intentional checkpoints to touch base (that are not part of data collection). Engaging participants and conveying gratitude throughout the research project is important because it operationalizes the key research ethics principles of respect, informed/ongoing consent, and concern for welfare.

## **2) Recruitment of family practices**

The goal of this project was to 1) develop a culturally-tailored GDM-focused KT tool for pregnant South Asians and their family physicians; 2) collaborate with two independently practicing family physicians (family practice in a solo or group practice with no associated interprofessional team) to pilot test the feasibility, acceptability, and interest for the KT tool. We were interested in working with independently practicing physicians because they may not readily have access to multi-disciplinary teams like family physicians who practice in family health teams or community health centres. The latter two groups work either alongside allied health professionals such as nurses, dietitians, kinesiologists, or alongside health promotion and

community development programs. Time and logistical barriers related to providing culturally-tailored healthy active living counselling (diet/nutrition and physical activity) may be more of a challenge for independently-practicing family physicians. This potential avenue to supplement the provision of relevant patient-oriented tools that are also evidence-based and theory-informed was a pragmatic decision. In future studies, it is possible to study the feasibility, interest, and acceptability of similar KT tools among diverse groups of prenatal clinicians. A component of this goal was to also build new community partnerships with physicians who our research team had not previously worked with in the Peel Region. After sending out over 40 personalized fax messages about this potential project and how to participate, we only received one expression of interest. I scheduled a meeting and visited this physician to discuss the project in more detail. After learning that only about 5% of his patients were of South Asian ancestry, we decided it would be optimal to begin with a higher-needs clinic. I then contacted our START Cohort Study coordinator (Peel region), to brainstorm a new plan for clinic recruitment. Upon their suggestion of two local family physicians who regularly see a high volume of South Asian women for prenatal visits (a form of a referral system), we scheduled meetings to discuss the study and see if it would be a good fit. After these meetings, two clinics were enrolled and both baseline visits were completed with the physician within a 2-week timeframe. The first clinic began recruitment immediately, whereas the second one did not receive any eligible participants over the first three months. After reassessment, we decided to approach the physician from the clinic 1 for a personal referral of a Peel region family practice physician who currently sees a high volume of pregnant South Asians (a form of snowball recruitment). Upon this referral, a new clinic 2 was on-boarded and began sending referrals immediately. With the partnership of these two clinics, we were successfully able to complete recruitment within a 7-month period and all follow-up before the end of the year.

It is important to note that the two family practices enrolled in the evaluation study were lead by physicians who self-identified as South Asian. This has potential implications regarding their level of engagement (interest and enthusiasm) in the study objectives and depth of feedback garnered (as they were likely to have a deeper understanding of Traditional dietary practices compared to non-South Asian clinicians). Also, their baseline level of knowledge, attitudes, and practices may have been higher due to their constant professional and personal engagement with the material.

Within our changing healthcare system, practice-based research is important in guiding improvements in clinical work environments and patient experiences. Engaging family practices is a challenging task because most family physicians have firm schedules. Important facilitators include the following: employing flexible recruitment strategies, front-office rapport, snowball sampling approaches, creating/building upon personal connections, devoting time to engagement, and creating strong promotional materials (including recognizable study logo). Many of these suggestions have been reported in other studies (e.g., 1), which only reiterates the need to approach with flexibility and nimbleness (i.e., iteratively review barriers, facilitators, challenges, and successes) so that recruitment strategies can be adjusted or re-envisioned as necessary.

### **3) Analysis**

In this section, I will review the key analytic considerations and rationales that were made within each of the primary projects and steps for future directions:

**1) Needs Assessment Study:** In this qualitative study we conducted a large focus group in English/Punjabi and translated the interviews into English prior to transcribing verbatim. Despite ample checkpoints, reviews, and translations completed in partnership with a professional service, there is still opportunity for thoughts, ideas, or insights to be “lost in translation.” South Asian languages are very descriptive and illustrative so when translated into English (despite accuracy and thoroughness), some of those imageries may be left out. This may impact the study because the emotional responses related to specific practices or behaviours may not be illustrated with the same level of influence, and thus may not be viewed as significant or important when compared to an interview conducted in English. The use of translation and back translation method, involvement of two to three translators, and prolonged engagement with translators during data analysis have been suggested in the current literature (2-7), and recently, Ho et al., 2019 developed a translation process rooted in social constructivism that aims to guide qualitative researchers (8). Despite the use of many of these suggested approaches, recommended improvements for future studies include 1) increasing transparency in the reporting of translation decisions; and 2) cultivating data analysis in the source language.

**2) Systematic Review and Narrative Synthesis of KT tools:** To learn from the experiences, perspectives, and theoretical nuggets presented in the systematic review and potentially glean information that can be transferred to higher income environments, we must acknowledge the concept of analytical generalization. Analytic generalization involves projecting transferability from evaluative studies based upon theoretical analyses of the factors that have produced the outcomes within a specific context (9). All the included studies were conducted in health contexts that are not considered similar to Canada. Thus, as far as we are aware, there have not been any

KT tools designed specifically for pregnant South Asians living in Canada or comparable health contexts. As research evidence suggests that 1) South Asians face unique experiences as it relates to risk factors and food choices/preferences during pregnancy; 2) there are anthropological and public health dimensions to health practices, developing culturally-tailored tools that can guide lifestyle counselling during primary care, can be of benefit for South Asians living in higher-income countries such as Canada. Being able to take the theoretical concepts from this systematic review to compile them as a foundational understanding for developing new tools. To bring these ideas together, I use the table describing general and specific characteristics and the ‘sailboat’ analogy to further explore the key components of these KT strategies and how they may be generalized to other contexts.

**3) Development of the ‘SMART START’ KT tool:** Although the KT tools consider and address the familial and broader contexts (e.g., in the suggested scripts, recipes, tips/tricks), they are conceptually designed for the individual pregnant person and not as a family-facing tool. We acknowledge the importance of familial approaches as it pertains to South Asian families, especially because we did see some multi-generational arrangements (about 30% of participants enrolled in the pilot evaluation live with parents/in-laws). In future editions of this evolving work, a family-facing tool that is guided by a broader socio-ecological framework can be developed. This way we can aim to engage the family unit (including multi-generational households) in lifestyle change.

**4) Evaluation of the SMART START KT tool:** the primary area of analytic considerations was related to decision-making around how to conceptualize the joint display and what specific

components to include. Joint displays exist along a gradient of depth and breadth; they can be too simple but can also quickly become very convoluted and complex. After reading a broad sample of mixed methods papers across different fields (including health and education) and attending webinars on the topic of joint displays, I made several versions of an initial display—first as a table, and second as a Venn diagram. I then read a paper (10), which inspired me to explore concentric displays. Concentric joint displays can help to illustrate sub-categories and how they relate to one another. This was particularly important because I wanted to delineate between the primary and secondary outcomes, directly illustrate the different strands, and how the intervention fared comparative to the control. Furthermore, colour coding also helped to define differences between outcomes, groups, and the qualitative and quantitative data. The circular approach helped to retain the bigger picture of the data while also helping to highlight the details.

### **Opportunities for (Immediate) Future Directions:**

First, I plan to use the suggestions provided by the participants and physicians enrolled in the evaluation component of this work to revise the KT tool so that it is more relevant and organized to better address knowledge gaps and needs. These suggestions include the following additions:

- specialized content for patients who are currently facing the challenges of obesity and who became pregnant while in the midst of weight reduction
- more information about community resources (e.g., especially for newer South Asian immigrants to the Peel Region)
- more education around the importance of weight control

- weaving in encouraging and motivational messages around up-keeping physical activity
- organize information by trimester
- include other related concerns such as isolation/mental wellbeing due to the pandemic/stay-at-home orders

Second, we were approached by other interested researchers in the field of obstetrics and maternal health to evaluate the KT tool package within larger networks of prenatal clinicians in Canada (e.g., Maternal health services in Hamilton) and India. The pilot evaluation data can be used to inform the design of this larger study, including study design (e.g., cluster Randomized Control Trial (RCT) by clinic site), sample size calculations, recruitment of clinics and participants, and the manual of operations.

Third, we can use the lessons learned from the qualitative strand of this evaluation study to contribute to the design and conduct of the DESI-GDM randomized control trial that is being led by principal investigator Dr. Russell de Souza. The DESI-GDM trial is a two-arm parallel RCT to assess the impact of a culturally tailored, personalized nutrition intervention on glycemic response to an oral glucose load in high-risk pregnant South Asians. A personalized nutrition plan will be developed for each pregnant person by a culturally congruent dietitian. This plan will respect faith-based food choices and regional preferences (e.g., North Indian vs. South Indian/Sri Lankan diet). The plan will be delivered by a culturally congruent health coach, and consider baseline dietary intake, energy-balance for recommended gestational weight gain, personal values and preferences, through setting 2-4 “SMART” goals. The following key points represent key counselling messages that can be incorporated into the intervention arm of the DESI-GDM trial:



information about how weight gain impacts labour and delivery, knowledge around the impact of GDM on the unborn baby and risk factors in addition to family history, personalized guidance (especially with respect to gestational weight gain), challenges around cravings (especially for sweets/sugars/chocolates), nausea, and the limited confidence in cooking/food preparation skills especially about Traditional South Asian foods. Regarding the last point, many also expressed that they need more than a recipe to confidently make South Asian meals (e.g., step-by-step video with detailed explanations) in addition to the fact that they may not be the primary food preparers in their households—it is either their mother, mother-in-law, or they order home cooked meals from a community takeout service. This means that is important to be aware that not everyone may benefit from food preparation messages. To address this issue in addition to other personal preferences, it would be important to inquire about the role the participant plays in their households (e.g., who is the primary food preparer) and the influence of multi-generational family arrangements. Advice can then be tailored around these specific considerations. Overall, this data suggests that future studies should be designed with participant-centered approaches and advice should be as tailored (individualized) as possible to support relevant and possible practice change.

## FIGURES



Figure 2. Virtual Participant Checkpoints during pregnancy

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## **PART C: Nested in (Research) Stories**

To bring together the components of this dissertation by demonstrating how research evidence is nested within an KT tool, which is nested within an evaluation, which is nested within community-facing KT products, I would like to present a short video collection. Unpublished elsewhere and produced specifically for this dissertation, this 15-minute film consists of two components, Part I: A different Kind of Story and Part II: Nesting dolls (See Appendix 1 for the full narration).

### **LINK TO VIDEO:**

[https://drive.google.com/file/d/1m9RXXK-Dr2D9K9Hzv\\_wMxdpe-UJ8BJD05/view?usp=sharing](https://drive.google.com/file/d/1m9RXXK-Dr2D9K9Hzv_wMxdpe-UJ8BJD05/view?usp=sharing)

This film opens with back-to-back scenes of me preparing a vegetarian meal (chopping spinach, sweet potato, lemons), pouring chai, and slicing up a mango. The visuals were specifically selected to draw comparisons between the research journey, the telling of a story, and the preparation of a meal. All three represent a goal-oriented process and are interwoven with different elements to reveal a beginning, middle, and end. This hook sets the stage and prepares the audience for a deeper dive into this dissertation (i.e., research story). Both parts are flanked with insights on how sharing stories connect us together by helping us individually and collectively grow and thrive.

Part I describes how and why I became interested in researching within the field of KT and the content area of CVD. I compare my experiences to that of germinating seeds and tending to plants. I draw on this comparison throughout this section to illustrate where this research falls

within the broader discourse and what the future may hold. I also include other reflections of nature (e.g., rain/storm) to illustrate changes in the literature/discourse.

Part II describes how each component of this dissertation is nested within each other. The research evidence is nested within the KT tool, which is nested within the evaluation, which is nested within the end-of-study KT products. I use the “Matryoshka Principle” and hand painted dolls as a metaphor to illustrate this nested design paradigm. I walk the audience through the meaning (ie., research story) behind each doll and conclude with how they all fit together.

## **Appendix 1: Video Narration**

### **[INTRO CREDITS]**

Every research study is a journey.

A journey for the researcher.

A journey for the participants.

A journey where clarity is defined, data is collected, organized, and presented.

Where ideas are rearranged, thoughts are pieced together, and a story is told.

An end product is revealed.

A contribution is made to the depth and breadth of a field of study.

A gift is given, left behind, for someone else to build upon.

But how you package that gift and how you choose to reveal your story may not only be parcelled with elements of surprise, but can also lead to community building, engagement, increased uptake, and response.

The telling of these stories is what connects us together. What helps us grow. What helps us thrive. What fills our souls and feeds our minds. We are ultimately nested in stories.

### **[FILM TITLE: NESTED IN (RESEARCH) STORIES]**

*“All that we are is story. It is what we arrive with. It is all that we leave behind”*

—Richard Wagamese

### **[PART 1 A different story]**

This story is a little different.

It is actually three stories nested into one big story.

And because of this, what was hard for me to decide on was whether I should start from the beginning or work backwards from the end. I also considered letting it unfold organically—but a fear of that was whether all my thoughts, convictions, and hopes would be thoughtfully shared.

But one thing I know for sure is that this research story you are about to hear is one that has been brewing for many years. And although it composes my entire dissertation, it is only a small contribution to the field that has been plowed, nurtured, and grown by the researchers, epidemiologists, public health professionals, and scientists who have come before me.

My journey begins as a speckle in that field, with the hopes of smashing the barriers between research and practice, between academia and community, between science and the arts.

And in the place of that barrier, to build bridges, passageways filled with lessons learned and challenges overcome so that others may take even a small nugget from this work and build it into their own.

That speckle of inspiration that fueled me, came many years ago, from my Masters research. For this project, I had the privilege of working with the Six Nations community to better understand perinatal health beliefs. And recognizing the critical role of co-design, joint data-analysis, and culturally-tailored communication changed my perspective of what it meant to be a researcher. And to understand that for all of this to unfold would be hard work but also good work, well that part, probably changed my life.

I reflected a lot on this. And it began to take me into the direction of knowledge translation. What does that mean to me? Well, I consider it like this:

Good quality knowledge is a lot like refreshing lemonade. Often stemming from a challenge, the research team makes it, the manuscript bottles it, the peer review tastes it, the journal sticks a label on it, and archive systems store it in a grocery store fridge for it to be purchased. But what if it's expensive to buy? Or shoppers don't know where to find it? Or its time consuming for shoppers to research the best brand?

Now enter, Knowledge Translation, the process of opening the bottle and serving it. It is a very intentional interdisciplinary effort.

I wanted to study this process more. I wanted to learn how it could be evaluated, improved, and scaled. I wanted to understand how I could make it more interdisciplinary. I wanted to learn how I could use multi-media and more engaging digital tools to translate evidence to different communities. While I was dreaming up ways I could achieve this, I was simultaneously introduced to an emerging public health challenge in my own community.

Being a South Asian woman, I have witnessed the impact that cardiovascular disease has had within South Asian communities. I have seen the impact of type 2 diabetes within my own family. And now learning that gestational diabetes (GDM) was on the rise in Southern Ontario was truly devastating. GDM is high blood sugar during pregnancy among women without previous diabetes and is also considered a condition that increases one's prospect of developing type 2 diabetes. This rising prevalence was the lemon. A public health challenge was before us. A priority population was being impacted and something had to be done.

**[PAUSE, Black screen]**

**[Part II Nesting dolls]**

Nesting dolls are associated with family and fertility. They are representations of the mother-child relationship, often seen as mothers carrying on the family legacy through their child in their womb. Metaphorically, nesting dolls are associated with a design paradigm known as the “Matryoshka principle.” It denotes an identifiable relationship of “objects within similar objects.”

And it all begins with the baby. The evidence. The most crucial doll. The first story. High-quality public health evidence from the South Asian birth cohort study was demonstrating that 36% of South Asian women would develop GDM. Compared to a rate of 5-10% in the general population, this was a problem. From this birth cohort of over 1000 mothers and babies from the Peel Region, Southern Ontario, we also learned more about risk factors in addition to family history and the importance of a high quality diet. We paired this evidence with other systematic reviews on perspectives of gestational weight gain, knowledge translation tools designed for this population, and a local needs assessment to better understand barriers and facilitators of lifestyle change among pregnant women and prenatal clinicians. From all this, we recognized there was a need for culturally-tailored resources that could address knowledge gaps, time related barriers, and logistical challenges in early prenatal care.

Taking this knowledge and nesting it within a tool, a set of resources that could help unlock that evidence. To do this, I worked with a graphic designer to create a tri-part multi-media toolkit for pregnant South Asians and their family doctors. This tool is represented by the second doll. The second story.

The patient facing version consists of 1) a video narrative that contextualizes the challenge around high GDM prevalence among pregnant South Asian women; 2) pocket-sized guidebook with personalized elements and suggested questions to inquire about at future clinic appointments; 3) summary reminder material in the form of a compact fridge magnet. The family physician-facing version consists of 1) resource kit; 2) laminated summary card with evidence-based information, suggested scripts, and links to supplementary resources.

To create this toolkit, we aligned our process with theories and frameworks and also injected components of arts-based considerations. We thoughtfully considered what types of illustrations, colours, images, text, paper, sizing, video/filming techniques, and narrative approaches we would use.

With the evidence nested in the tool, the tool was then nested within an evaluation. This evaluation was conducted in partnership with two local family practices in the Peel region. We wanted to understand the feasibility, interest, and acceptability for this tool, but also to explore if it could be a way to improve knowledge, attitudes, practices, and confidence. We found that this topic had a high degree of interest, feasible recruitment, and good retention. Pregnant patients valued the new information they learned, changed some diet and physical activity practices, and made recommendations to improve the content and layout of the toolkit.

We then nested the results from this evaluation into a final community-facing production, a production that weaves together two artistic pieces: a digital illustration and a short film. This is the fourth doll. The fourth story. I partnered with a South Asian illustrator and artist to take the findings from the evaluation study to create a visual representation that can be used to foster



conversation among communities of interest, to build bridges between research and community and science and the arts.

The two of us had a long email thread and one detailed video conference to co-create a plan for how to this. We prioritized the key results with the concept that lifestyle counselling about GDM is a ceremony between physicians and patients, where it is vital to meet pregnant women where they are and build the advice on top of that. We discussed building the piece on the literal and figurative stethoscope that lies between them. The headpiece, which symbolizes the physician's perspectives; the chest piece that symbolizes the patient's perspectives; and the connecting cord which symbolizes shared views and expectations. At the headpiece we see the use of different South Asian languages to better connect, use of open-ended questions, and the understanding of personal, familial, and cultural influences. At the chest piece, we see the pregnant woman's perspectives around dietary preferences, South Asian traditional foods, influence of elder women, and the challenges of cravings, monitoring glucose, and controlling pregnancy weight gain. The connecting cord is adorned with gold bangles—a traditional representation that goes back to ancient civilizations and symbolizes more than just ornamentation. It represents cultural norms, practices, and rituals as they relate to the auspiciousness of unities and the role of fertility, pregnancy, and child rearing. In the illustration, the cord begins with thin bangles and as we go closer to the chest piece, they become thicker and more prominent. This symbolizes the building and strengthening of trust between pregnant patients and their family physicians.

Building from this illustration to create this short film is also a process that involved reflection and interdisciplinary partnerships. It included writing, editing, and finalizing a script, audio-recording the script, planning out a storyboard, filming, editing, re-filming, re-editing....but the most important part is finding the story. And using visuals to enhance the words. It is looking for the thread that weaves together all of the individual components in a meaningful way. In some cases it may be a metaphor, a personal narrative, or the interweaving of both. Either way, it re-iterates the idea that every study is a journey, a story. It can be told, built upon, and re-told. The telling of these stories is what connects us together. What helps us grow. What helps us thrive. What fills our souls and feeds our minds. We are ultimately nested in stories.

“When we take the time to share stories with each other, we get bigger inside, we see each other, we recognize our kinship – we change the world, one story at a time.” -Richard Wagamese