Assessing Patient Experiences
to Improve Nutrition and Physical Activity Services
in Primary Care

by

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ABSTRACT

ASSESSING PATIENT EXPERIENCES TO IMPROVE NUTRITION AND PHYSICAL ACTIVITY SERVICES IN PRIMARY CARE

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University of Guelph, 2014

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Paula Brauer

The overall aim of this research was to develop a self-report questionnaire to assess patient experiences of nutrition and physical activity services offered in interdisciplinary primary care settings. Thirty-eight providers individually rated and ranked Wong and Haggerty’s dimensions/sub-dimensions of patient experience of primary health care after group discussions. Items from existing patient questionnaires were modified and new items generated. The draft questionnaire was revised based on two rounds of cognitive interviewing with 11 patients and feedback from experts. Dimensions/sub-dimensions included in the questionnaire are: first contact-accessibility, trust, whole-person care, general communication, respectfulness, shared-decision making, economic accessibility, team functioning, services provided, and patient activation. The draft questionnaire consists of 23 questions that address the key interests of providers and patients. The questions demonstrate face validity based on expert review. The questionnaire length is feasible based on patient feedback and it is ready to be implemented and tested further in quality improvement initiatives.
Acknowledgements

I would like to acknowledge Dr. Paula Brauer, whose advocacy and leadership in primary care dietetics has influenced my career and my decision to return to graduate studies. I especially appreciate the opportunities to be involved in the early brainstorming of this project, to discuss bigger picture primary care issues, and for patient guidance through this process. I am grateful for the thoughtful review and feedback from committee members Dr. Donna Lero and Dr. John Dwyer.

I would not have been able to do this project without the FHT health care providers and patients who were willing to share their time and expertise with me – my sincerest thanks.

I am grateful for the support and encouragement of my colleagues and friends, especially the RDs and colleagues of the FHT where I work and the Ontario FHT RD Network. I am thankful to Tracy Hussey for supporting my professional goals and for allowing flexibility to do so.

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<td>Community Health Centre</td>
</tr>
<tr>
<td>CI</td>
<td>Cognitive Interviewing</td>
</tr>
<tr>
<td>CIHI</td>
<td>Canadian Institute for Health Information</td>
</tr>
<tr>
<td>CSE-PHC</td>
<td>Canadian Survey of Experiences in Primary Health Care</td>
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<tr>
<td>DG</td>
<td>Discussion Group</td>
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<tr>
<td>ED</td>
<td>Executive Director</td>
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<tr>
<td>FHT</td>
<td>Family Health Team</td>
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<tr>
<td>QI</td>
<td>Quality Improvement</td>
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<td>RD</td>
<td>Registered Dietitian</td>
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Chapter 1: Introduction

The overall aim of this research study was to develop a tool to assess patients’ experiences with nutrition and physical activity (lifestyle) services offered in interdisciplinary primary care settings that can be used for evaluation and quality improvement purposes. There are currently no patient experience questionnaires that are team practice oriented and related to lifestyle services. The purpose of this research project was the initial development of such a questionnaire. This questionnaire begins to fill an important gap in the evaluation of lifestyle services in primary care and will be available to other interdisciplinary teams that want to include this source of information in their evaluation of patient-centered services. This newly developed questionnaire uses the most up-to-date theoretical framework of the dimensions of patient experiences in primary health care and aligns with the current health care reform emphasis on quality improvement. The questionnaire could be widely used in the primary care lifestyle services setting and be adapted to other contexts.
Chapter 2: Background

Primary Health Care Reform in Canada

Health care reform in Canada over the past 10 years has led to the development of a greater variety of interdisciplinary models of primary care. Team-based care is envisioned as one of the four foundational building blocks of high performing primary care (Bodenheimer, Ghorob, Willard-Grace, & Grumbach, 2014). Newer models incorporate registered dietitians (RDs), kinesiologists and physiotherapists, pharmacists, psychiatrists, mental health counsellors, occupational therapists and others into teams with family physicians, nurses, and nurse practitioners. During a meeting in 2004, the First Ministers established a goal of at least 50% of Canadians having access to interdisciplinary primary health care teams by 2011 (Health Canada, 2006). Progress varies between provinces. In the 2008 Canadian Survey of Experience in Primary Health Care, 27% of respondents reported a nurse was involved in their care and 16% reported other interdisciplinary primary care members were involved in their care (CIHI, 2009). In 2010, just over 16% of Ontarians were rostered to physicians in interdisciplinary primary care teams (Glazier, Zagorski, & Raynor, 2012). The general consensus is that interdisciplinary models will improve the ability of primary care teams to provide better access to care, better quality of care more efficiently, and be able to offer comprehensive preventative care and chronic disease management (Aggarwal & Hutchison, 2012). Team-based care has demonstrated improved care and clinical outcomes (Manns et al., 2012), the potential for a reduction in type 2 diabetes complications, and significant direct and indirect cost savings to the health care system (Dinh & Bounajm, 2013).

Among primary care services, prevention services are among the most challenging to develop and evaluate (Health Council of Canada, 2013). Primary and secondary prevention
efforts in primary care are gradually increasing, as groups work to shift some of the focus away from treatment towards keeping people healthy (Aggarwal & Hutchison, 2012). Preventative services include screening for illness as well as addressing modifiable risk factors such as unhealthy diet, inactivity, alcohol overuse, and tobacco use. These factors need to be addressed at the policy, population, and individual levels. In the primary care setting, efforts focus at the individual level to address diet and physical activity related issues by providing lifestyle services. From the patient’s perspective, family doctors provide infrequent diet and exercise advice (Brauer, Sergeant, Davidson, Goy, & Dietrich, 2012) and family doctors identify barriers of time, inadequate training, and reimbursement (Petrella, Koval, Cunningham, & Paterson, 2003; Wynn, Trudeau, Taunton, Gowans, & Scott, 2010). Opportunities exist to provide health promotion and disease prevention in primary care with RDs (Brauer et al., 2006b) and qualified physical activity counsellors (O’Sullivan et al., 2010).

Management of Lifestyle Related Conditions in Primary Health Care Settings

Cardiometabolic conditions, a set of risk factors associated with the development of cardiovascular disease and/or type 2 diabetes (Leiter et al., 2011a), are often managed in primary care. Canadian practice guidelines on diabetes prevention and management (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013), hypertension (Daskalopoulou et al., 2012), dyslipidemia (Anderson et al., 2013), obesity (Lau et al., 2007), and metabolic syndrome (Leiter et al., 2011b) all promote use of lifestyle changes to reduce medication use and prevent or slow the progression of disease. The evidence is especially strong for the ability of lifestyle changes to prevent or delay progression of pre-diabetes to type 2 diabetes (Saaristo et al., 2010; Diabetes Prevention Program Research Group, 2009; Diabetes Prevention Program Research Group, 2002). Often the most effective lifestyle changes are diet related and while
there may be many different health care providers working with patients on lifestyle changes, such as nurses, kinesiologists, and health promoters, registered dietitians are most specialized for managing nutrition therapy (Brauer, Dietrich, & Davidson, 2006). Lifestyle interventions focus on facilitating behaviour change and involve assessing readiness, adapting the approach and messaging to the individual patient, and preventing attrition (Delahanty, 2010). As of 2013, approximately 18% of registered dietitians in Ontario were working in interdisciplinary primary care teams such as Family Health Teams (FHTs) and Community Health Centres (CHCs), not including those working in public health (College of Dietitians of Ontario, 2013). RDs manage nutrition services from direct care and program development to supporting the team in their nutrition related activities (Brauer et al., 2006). The top three reasons for referral to RDs in primary care are for weight management, diabetes prevention or management, and modifiable cardiovascular risk factors (Brauer et al., 2006a). In some settings, these conditions account for over 85% of referrals (Crustolo, Ackerman, Kates, & Schamehorn, 2005; Gamblen et al., 2007).

**Evaluating Primary Care**

Primary care teams are engaging in quality improvement initiatives to provide a better patient experience, improve the health of the population, and increase efficiencies. To evaluate care, there need to be common measures for different facets of primary care. Over the past decade, significant work by the Canadian Institute for Health Information (CIHI) and other groups has resulted in the development of primary health care quality indicators (Glazier et al., 2012; CIHI, 2006; CIHI, 2012), attributes of quality primary care (Haggerty et al., 2007; Levesque et al., 2011), and dimensions of the patient experience in the primary health care setting (Wong & Haggerty, 2013). This work informs which aspects of primary care to evaluate and the best data sources to evaluate them. Different provinces are taking differing approaches,
but all are committed to quality improvement. For example, starting in April 2013, all FHTs in Ontario must develop Quality Improvement Plans, identifying their objectives and measurement plans for improvement in the areas of access, continuity of care across sectors, and patient-centred care (Ontario Ministry of Health and Long Term Care, 2013).

**Patient Experience of Primary Care**

Patient centeredness is a core value of dietetics practice (Steinecke & College of Dietitians of Ontario, 2013), medicine (The College of Family Physicians of Canada, 2011), and nursing (Registered Nurses' Association of Ontario, 2006). Patient experience and satisfaction with service are important indicators of quality of care. Patient experience is positively associated with clinical safety and effectiveness (Doyle, Lennox, & Bell, 2013) and evaluating the patient experience can identify tangible areas for service improvement (Bleich, Ozaltin, & Murray, 2009). Developmental work on primary health care attributes and indicators suggests certain aspects of care are best assessed by asking patients (Haggerty et al., 2007). Asking patients about their satisfaction with service is only one aspect of the patient experience and tends to be highly favourable (Salisbury, Wallace, & Montgomery, 2010). There is also evidence that patients can rate high satisfaction with care at the same time as they describe suboptimal experiences (Jenkinson, Coulter, Bruster, Richards, & Chandola, 2002). There are many ways to elicit the patient experience – including having community boards or advisory groups, using complaints systems, patient stories, interviews, surveys, and focus groups (de Silva, 2013). Each approach has strengths and limitations. Patient surveys are one way to support quality improvement and ensure a focus on patient-centred care, rather than provider-centred care (Haggerty, 2011). Surveys are able to identify generalizable issues that organizations can address.
to improve services and can be more or less descriptive depending on the questions included and the answer formats (de Silva, 2013).

**Patient Experience Questionnaires**

Acknowledgement of the importance of including patients’ experience of care has led to the development of numerous questionnaires that assess various combinations of attributes of primary care from the patient perspective. Haggerty et al. (2007) undertook a process to define primary care attributes, which has resulted in a solid theoretical framework for the development of primary care questionnaires in Canada. Building on this work, Wong and Haggerty (2013) propose a set of six dimensions of patient experience in primary health care. Their work guided the latest national CIHI patient experience survey released in April 2013 (CIHI, 2013). Many of the primary care experience questionnaires to date have been focused on the overall primary care experience and notably physician practice (Levesque et al., 2012). Several groups have compiled lists of surveys for evaluating patient experience in the primary care setting (S. Ackerman, personal communication, 2013; de Silva, 2013; Haggerty, 2011). These lists provide a starting point for review of questionnaire content, formatting, and wording. For a summary of selected general primary care surveys, see Appendix A. Very few of these surveys contain questions referring to lifestyle advice by primary care providers or ask patients about lifestyle services available within their primary care setting.

A search for questionnaires used for patient feedback on nutrition or lifestyle services found primarily satisfaction surveys, many asking about RD skills and manner (A. Mayhew, personal communication, Undergraduate project, 2012). This work was reviewed and additional surveys were found through a literature search and manual search of article references. For a summary of selected nutrition services and diet-related questionnaires, see Appendix B.
Questionnaire Development

Questionnaire development for patient experience is a challenging process. It is important to create a questionnaire that meets the needs of primary care practitioners and engages both providers and patients in the process. New questionnaire development involves a great deal of thought and resources. There are various methods described for the development of a new questionnaire. Steps described by Crawford (1997) provide a general guide to the process. These steps include deciding what information is required, determining the question content, developing the wording, arranging questions in an appropriate format, and pre-testing the questionnaire to develop the final version.

Determining the purpose of the questionnaire, whether to conceptualize the patient experience as categorical (positive experience or experience that could be improved) or dimensional (on a continuum of the experience), and how to establish some level of reliability and validity are important aspects to consider (Streiner & Norman, 2008). With a patient experience questionnaire designed to guide the quality improvement process, it may be preferable to use a categorical model conceptualization. By identifying cases of experiences that are positive and cases that require improvement, providers could set benchmarks for their quality improvement process and focus on increasing the positive experiences. Face validity of a questionnaire, or determining that the questionnaire appears to measure what it is intended to measure, establishes a starting point from which further psychometric testing can be conducted.
Chapter 3: Rationale, Goal, and Objectives

Rationale

Lifestyle interventions are a critical component of preventive health care services. In the past decade of health care reform in Canada, lifestyle services have become increasingly available with the inclusion of registered dietitians, kinesiologists, and others in interdisciplinary models of primary care. Patient experience is recognized as an important aspect of assessing the quality of health care received, yet questionnaires to date have focused mainly on physician care or satisfaction with interpersonal aspects of individual lifestyle service providers. Existing nutrition-specific or provider-specific primary care patient evaluation tools do not suffice. New questionnaires that address the range of issues relevant to the patient experience of team-based lifestyle services are needed to support ongoing quality improvement initiatives. It is expected that this type of questionnaire needs to be a short, self-administered, generic tool that addresses the main concepts of the patient experience and is feasible to offer in a range of primary care lifestyle programs.

Goal: To develop a generic, self-administered patient experience questionnaire for lifestyle services in the interdisciplinary primary care setting.

Objectives:

1. Identify aspects of the patient experience of lifestyle services that providers desire to be assessed, using a health services patient experience framework.

2. Draft a questionnaire based on existing patient experience questionnaire items and new items as needed.

3. Establish face validity with expert review of the questionnaire.
4. Modify the questionnaire based on feedback from patient interviews and primary health care lifestyle services experts.
Chapter 4: Research Design and Methods

This questionnaire development project consisted of two main phases. The first phase was to determine the high priority topics to include in the questionnaire by consulting with primary care providers and primary care lifestyle service experts. We used cross-sectional survey methods and convenience sampling to get initial provider input. The second phase involved generating the first draft of the questionnaire and making modifications based on feedback from primary health care lifestyle service experts and patients who had participated in lifestyle services. Cognitive interviewing (CI) was conducted with a convenience sample of primary care patients who had recently participated in lifestyle services. Approval for this study was obtained from the University of Guelph Research Ethics Board (Appendix C).

Conceptual Framework Guiding the Project

Dimensions to include in patient experience questionnaire. Haggerty et al. (2007) conducted a Delphi process with Canadian primary health care experts to develop operational definitions that would support measurement and evaluation of primary health care attributes. This work resulted in 25 dimensions to assess the quality of primary health care from several data sources: provider, patient, chart, and administrative data. In 2013, Wong and Haggerty then extended this work. Informed by the Framework for Primary Care by Hogg et al. (2008) and the Primary Health Care Logic Model by Watson et al. (2009) they developed dimensions of the patients’ experience in primary health care. This new framework organizes aspects of patient experience into six dimensions: access, interpersonal communication, continuity and coordination, comprehensiveness of services, trust, and patient-reported impacts of care. Five of these dimensions are further broken down into 16 sub-dimensions. The dimension of trust does not have any sub-dimensions. Table 1 lists these dimensions, sub-dimensions and the definitions.
as presented by Wong and Haggerty (2013). These dimensions/sub-dimensions of patients’
experience were used as the framework for determining which aspects to include in the
questionnaire.

Table 1: Wong and Haggerty’s dimensions and sub-dimensions of patients’ experiences in
primary health care with definitions.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Sub-dimension</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Access</td>
<td>First contact accessibility</td>
<td>The ability to obtain patient- or client-initiated needed care (including advice and support) from the provider of choice within a time frame appropriate to the urgency of the problem.</td>
</tr>
<tr>
<td>Accommodation</td>
<td></td>
<td>The relationship between how resources are organized to accept patients or clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the patients’ ability to accommodate to these factors to realize access.</td>
</tr>
<tr>
<td>Economic accessibility</td>
<td></td>
<td>The extent to which direct and indirect costs relate to care impeded decisions to access needed care or continue recommended care.</td>
</tr>
<tr>
<td>Interpersonal communication</td>
<td>General communication</td>
<td>The ability of the provider to elicit and understand patient or client concerns, and to explain health and health care issues.</td>
</tr>
<tr>
<td></td>
<td>Respectfulness</td>
<td>The ability of the primary care organization and practitioners to provide care that meets the expectations of users about how people should be treated, such as regard for dignity and provision of adequate privacy.</td>
</tr>
<tr>
<td></td>
<td>Shared decision-making</td>
<td>The extent to which patients or clients are involved in making decisions about their treatment.</td>
</tr>
<tr>
<td>Whole-person care</td>
<td>Relational continuity</td>
<td>A therapeutic relationship between a patient or client and one or more identified providers that spans separate health care episodes and delivers care that is consistent with the patient’s or client’s biopsychosocial needs.</td>
</tr>
<tr>
<td></td>
<td>Informational continuity</td>
<td>The extent to which information is used to make current care appropriate to the patient or client.</td>
</tr>
<tr>
<td>Coordination</td>
<td>Coordination</td>
<td>The provision and organization of a combination of health services and information with which to meet the patient’s or client’s health needs, including services available from other community health service providers.</td>
</tr>
<tr>
<td>Dimension</td>
<td>Sub-dimension</td>
<td>Definition</td>
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<tr>
<td>----------------------------</td>
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<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Team functioning</td>
<td></td>
<td>The ability of primary health care providers to work effectively as a collaborative team to manage and deliver quality patient or client care.</td>
</tr>
<tr>
<td>Comprehensiveness of services</td>
<td>Services provided</td>
<td>The provision, either directly or indirectly, of a full range of services to meet patients’ or clients’ health care needs. This includes health promotion, prevention, diagnosis and treatment of common conditions, referral to other clinicians, management of chronic conditions, rehabilitation, palliative care and, in some models, social services.</td>
</tr>
<tr>
<td>Health promotion and primary prevention</td>
<td>Health promotion</td>
<td>Health promotion is the process of enabling people to increase control over, and to improve, their health. Primary prevention is directed towards preventing the initial occurrence of a disorder.</td>
</tr>
<tr>
<td>Trust</td>
<td></td>
<td>An expectation that the other person will behave in a way that is beneficial and that allows for risks to be taken based on this expectation. For example, patient or client trust in the physician provides a basis for taking the risk of sharing personal information.</td>
</tr>
<tr>
<td>Patient-reported impacts of care</td>
<td>Patient activation</td>
<td>Patient’s or client’s ability or readiness to engage in health behaviours that will maintain or improve their health status.</td>
</tr>
<tr>
<td>Patient safety</td>
<td></td>
<td>Patient’s or client’s reports of medication errors (given or taken the wrong drug or dose) or incorrect medical or laboratory reports and communication with their provider about not taking their prescribed medication or medication side effects.</td>
</tr>
<tr>
<td>Confidence in the PHC system</td>
<td></td>
<td>The perception that allows patients or clients of health care to make decisions since they assume (and expect) relative certainty about providers delivering safe and technically competent care.</td>
</tr>
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(Wong & Haggerty, 2013)
Phase 1: Health Care Provider Discussion Groups

We desired provider input to identify and prioritize which aspects of the patient experience of lifestyle services to include in the questionnaire. We held discussion groups with two purposes in mind: 1) to orient the group to the newly released Wong and Haggerty framework in order to facilitate rating and ranking the dimensions/sub-dimensions, and 2) to get a sense of the concepts that providers would want to include on the questionnaire.

Participants

*Family health teams.* Five FHTs participated in the discussion groups. These primary care teams represent one rural FHT, three urban non-academic FHTs, and one urban academic FHT.

*Health care provider participants.* A total of 38 providers attended discussion groups which ranged in size from four to ten participants. Participant characteristics are presented in Table 2. Most identified as female (92%), the average age was 40, and there were multiple provider categories represented including nursing, dietetics, mental health, and administrative. There were no family doctors in the discussion groups. On average, participants had been in their profession for 14 years and had worked in their FHT for 3.8 years.
There were 12 discussion group participants and five members from additional FHTs, not involved in discussion groups, who expressed interest in providing feedback on a summary of the discussion group results. There were 7 responses to this summary and one of these was from a FHT member who did not participate in the discussion groups.
Measures.

**Facilitator guide.** A facilitator guide (Appendix D) was used to support a consistent process for the moderators. This guide highlighted the following questions for the facilitator to pose to participants during the discussion groups:

1. Are there any sub-dimensions that particularly seem important to include when thinking about evaluating the patient experience of lifestyle services in primary care?
2. Are there specific types of questions within these sub-dimensions that you think would be helpful when you consider making quality improvements to lifestyle services?
3. Are there any aspects that are missing from these sub-dimensions that you would like to receive patient feedback on?

**Rate and rank survey.** We developed a survey for rating and ranking the Wong and Haggerty dimensions/sub-dimensions (Appendix F). Each dimension is listed in the first column along with the breakdown of the sub-dimensions in a second column, including abbreviated definitions. The third column contains a Likert scale of 1 to 5 for rating the importance of that dimension or sub-dimension, where 1 is very important, and 5 is not at all important. The importance rating is completed on each of the sub-dimensions plus the dimension of trust. The trust dimension does not have any sub-dimensions. The fourth column is blank for participants to rank the importance of their top five dimensions/sub-dimensions to include in the questionnaire, where 1 is the top priority.

**Provider demographics questionnaire.** We developed a questionnaire to collect demographic information from the participants of the discussion groups (Appendix F). This
information included age, gender identity, professional specialty, regulatory college, years practicing, and years practicing in their current primary care team.

Procedure.

Recruitment. We used a list of 170 Ontario FHTs, with ED’s contact information from a 2012 research project, to recruit FHT providers. This contact list was originally collected from a public listing of FHTs on the Ontario Ministry of Health and Long-Term Care website and each FHT was contacted to update ED names and email addresses (C. Bonilla, personal communication, 2013). In November of 2013, we updated the contact information for FHTs within a two-hour driving distance of Guelph, Ontario based on public information found on FHT or community information websites. A two-hour driving distance was used for travel feasibility and was determined by using the Google Maps driving directions feature. From the list of 170 FHTs, 88 were determined to be within a 2-hour drive of Guelph, Ontario. Of these 88, there was no email address available for 20, therefore 68 emails were sent to FHT executive directors (EDs). Ten of these emails were returned not having reached their intended recipient.

We sent FHT EDs an email introducing the questionnaire development project and inviting their FHT’s participation (Appendix G). We also sent an email to a listserv of over 300 Ontario FHT RDs encouraging them to discuss this research project with their EDs (Appendix G). From the 58 emails successfully sent and FHT RD listserv advertising, 17 FHT EDs or representatives responded with an interest in participating in this project. This is a response rate of 29.3% of the FHTs sent direct emails.

The first five FHTs to commit to a discussion group date were included in the study. We used a convenience sample to increase the likelihood of participants with an interest in lifestyle services evaluation. EDs were responsible for recruiting a minimum of five providers (health
care professionals and administrative staff) and arranging an appropriate meeting space. FHTs that expressed interest in the project but were not scheduled for a discussion group had the opportunity to offer feedback on the summary of health care provider discussion group results. As I am an employee of a FHT, health care providers from that FHT were not included in discussion groups.

Discussion group sessions. We held five discussion group sessions with providers at the different FHT locations during participants’ lunch hour. Independent professional moderators were hired to facilitate the discussion groups. We created a visual depiction of the Wong and Haggerty dimensions/sub-dimensions (Figure 1). We did this based on the recommendations of our primary moderator to have a document with visual cues to facilitate the discussion rather than the use of worded definitions.
Figure 1: Visual representation of Wong and Haggerty's dimensions and sub-dimensions of patient experience in primary health care
Due to moderator availability, there was one moderator for the first three sessions and a different moderator for each of the last two sessions. Prior to their session, the participants were sent the visual depiction of the framework along with the consent form (Appendix D) to facilitate easier review and discussion. Sessions were 60 minutes in length with or without an additional 30 minutes to include a meal. Lunch was provided to all participants. The moderator explained the purpose and process of the discussion group and questions were answered. Participants provided written informed consent prior to beginning the group session. Sessions were audio-recorded and I attended to take notes on the main concepts discussed. The moderator guided the participants through a discussion of the dimensions and sub-dimensions of patient experiences in primary health care being considered for inclusion in the questionnaire. Discussion was guided by a facilitator guide (Appendix D) and elicited participants’ ideas of aspects most important to include in a patient experience questionnaire of lifestyle services.

Participants then individually completed the rate and rank survey (Appendix E) to identify their priorities and evaluate the dimensions/sub-dimensions in two ways: 1) rate the importance of each of the dimensions/sub-dimensions, and 2) select their top five dimensions/sub-dimensions and rank them from one to five. All participants completed a demographics questionnaire (Appendix F) and those who were interested in reviewing a summary of all of the discussion group results provided their name and email address (Appendix I). There was no financial remuneration offered.

**Member-checking.** After all of the discussion group sessions were finished, a summary of the rate and rank results along with highlighted discussion group comments from the note-taking was sent by email to interested providers for member-checking. Providers were asked to review the summary and provide comments on the results compared to their own views. They
were asked if there were any surprises and to add any additional points that should be considered in our questionnaire development. Respondents provided comments by email.

**Analysis.** We used Microsoft Excel for descriptive statistics of participant characteristics and for the analysis of rate and rank survey results.

*Dimension/sub-dimension rating and ranking.* Using the rating responses, the dimensions/sub-dimensions importance rating was averaged across all participant responses, with lower averages indicating higher importance. Using the ranking responses, each dimensions/sub-dimensions was given a total importance score to inform prioritization, with higher scores indicating higher prioritization for inclusion in the questionnaire. This total score was calculated by giving a score of 5 for top rank, 4 for the second rank, 3 for the third rank, 2 for the fourth rank, and 1 for the fifth rank. Total scores were calculated for each dimension/sub-dimension overall and by discussion group. The total number of top five rankings for each dimension/sub-dimension was also tabulated. Dimensions/sub-dimensions were then given a priority rank by discussion group score and an overall priority rank by total score. There were a few ties, which were broken by using the number of participants ranking the dimension/sub-dimension in the top five.

*Discussion group content and member-checking.* Initial discussion group notes were supplemented by reviewing the audio-recordings. Notes of the comments made during group discussions were compiled by dimension and colour-coded by discussion group. Additional comments from the member-checking feedback were added to the summary of discussion content. We reviewed and discussed the notes to determine the main concepts we wanted to include within the questionnaire.
**Health care provider discussion group post-hoc analysis.** After making revisions to the questionnaire and reviewing the health care provider discussion group notes, we decided to analyze the discussion groups further to explore and potentially explicate the rate and rank results and main concepts that came through. We also wanted to explore how participants discussed Wong and Haggerty’s patient experience dimensions/sub-dimensions, their understanding of the definitions, and examples of how they related their understandings to the lifestyle services context. Four of the five groups were transcribed as one audio-recording was mistakenly deleted. We used qualitative content analysis, defined as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005 p. 1278). There are several different types of qualitative content analysis and we used directed content analysis as described by Hsieh and Shannon (2005) since it is generally used to add to existing frameworks or theories. Data that related to discussion of the dimensions/sub-dimensions were highlighted, differentiating between the six dimensions. Highlighted text was then further reviewed and attention given to words used to describe dimensions/sub-dimensions, the relationship between the dimensions/sub-dimensions, and the use of the dimensions/sub-dimensions when discussing lifestyle services. We identified some general themes and observations, with quotes for illustration.

**Phase 2: Developing and Modifying the Questionnaire**

We developed a first draft of the questionnaire and then made modifications based on feedback from expert review and patient interviews. Individual in-person cognitive interviews with patients who had participated in lifestyle services were used to identify questionnaire issues related to instruction and question understandability, ease of formulating a response, and
questionnaire formatting. Participants were also asked for input on various aspects of the questionnaire. An opportunity to consult a group of eight Canadian primary care lifestyle service researchers arose. They provided feedback on the questionnaire and reviewed the questions for face validity. This group included experts in primary care research and lifestyle change who have backgrounds in epidemiology, nutritional sciences, kinesiology, and family medicine. Their comments via email were taken into consideration when making revisions.

Participants

Sample size justification. There is minimal evidence regarding optimal sample sizes for cognitive interviewing, and recommendations from experts in the field support samples as small as four or five (Willis, 1999). Work by Blair and Conrad (2011) provides some empirical data to guide cognitive interviewing sample size. They simulated different sample sizes from a pool of 90 cognitive interviews to determine the number of problems identified and impact level of those problems. The impact level was a measure of the frequency (how often the problem occurred) and severity (likelihood of the problem to effect measurement) of the problem. They found that a sample size of 5 identified just under 25% of the total number of problems and almost 40% of the highest impact problems. With even small increases in sample size, from five to 15, the number of problems identified doubled and the proportion of highest impact problems identified increased from just below 40% to greater than 60%. A sample size of 50 or more would be required in order to capture over 80% of the problems. Ryan et al. (2012) acknowledge the challenge of balancing costs and benefits of cognitive interviewing in small and medium-scale evaluations and endorsed a multi-method (cognitive interviewing, expert review, literature reviews), and multi-iterative approach. A sample size of 10-15 is therefore a balance of problem identification and feasibility within the context of this small-scale project.
Cognitive interviewing participants. From a group of 25 FHT nutrition program group attendees, 18 expressed interest in participating in this project. Interviews were successfully scheduled with 11 of these individuals from the group sessions. As I am an employee of a FHT, patients recruited were not from clinics where I worked at the time of the study.

Participants were primarily female and ranged in age from 32 to 78 with an average of 56.6 years. Their average reported years of education was 13.4. Over half of the participants had six or more appointments at their family doctor’s office in the past 12 months and their family doctor, RD, and mental health counsellors were most often reported as the provider they met with. Demographic details are available in Table 3.
Table 3: Cognitive interviewing participant demographic characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cognitive interviewing participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>average</td>
</tr>
<tr>
<td>Age, years</td>
<td>57 (32-78)</td>
</tr>
<tr>
<td>Years of education</td>
<td>13</td>
</tr>
<tr>
<td>Years with current family doctor</td>
<td>20</td>
</tr>
<tr>
<td>Gender identify, female</td>
<td>n</td>
</tr>
<tr>
<td>No. of visits at family doctor’s office in past 12 months</td>
<td>10</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1-2</td>
<td>3</td>
</tr>
<tr>
<td>3-5</td>
<td>2</td>
</tr>
<tr>
<td>6 or more</td>
<td>6</td>
</tr>
<tr>
<td>Appointments in past 12 months with following health care provider</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td>7</td>
</tr>
<tr>
<td>Family doctor</td>
<td>11</td>
</tr>
<tr>
<td>MH</td>
<td>6</td>
</tr>
<tr>
<td>NP</td>
<td>4</td>
</tr>
<tr>
<td>Nurse</td>
<td>4</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

Measures.

First draft questionnaire. The first draft of the questionnaire (Appendix J) included a short introduction modeled on the CIHI patient experience questionnaire instructions and consisted of 30 questions. The intention was for patients to complete the questionnaire considering all of the lifestyle services they had attended/received through their family doctor’s office over the past 12 months. Face validity was established from research committee and expert research group review.

Cognitive interviewing guide. A CI guide (Appendix K) was used to support a consistent process for interviewing each participant. It included prompts that are question specific as well
as prompts that are based on participant behaviours such as pausing, using a questioning tone when answering, and engaging with the interviewer.

**Participant demographic questionnaire.** We developed a questionnaire to collect demographic information from the participants of the CI sessions (Appendix L). This information included age, gender identity, highest education level completed, and questions related to health care utilization.

**Second draft questionnaire.** The second draft of the questionnaire was modified based on the first round of CI sessions, as well as feedback from expert research review. It consisted of 22 questions. The introductory section includes an emphasis on team members and a space to include a description of the lifestyle program being evaluated.

**Procedure.**

**First draft questionnaire development.** The main concepts to include in the first draft were determined after considering various inputs. These included the provider dimensions/sub-dimensions rating and ranking results, the notes taken from the discussion groups, the additional member-checking feedback from participants, the expert research group feedback, and reflection on my own primary care work experience.

A selection of primary care and dietetics patient questionnaires was reviewed and each item categorized using the Wong and Haggerty dimensions/sub-dimensions of patient experience in primary health care. Questions were narrowed down based on the dimensions/sub-dimensions chosen to be covered and further reduced to items that addressed key concepts of interest. Existing items were modified to fit the team-based lifestyle services context and adapted for consistent and favourable formatting. New items were generated if suitable questions were not found. We reviewed this first draft for face validity and for readability.
Recruitment. One FHT was asked to support patient recruitment when FHTs were initially recruited for health care provider discussion groups. Adults accessing lifestyle services (group or individual) at one large FHT were recruited at four group education sessions or by RDs at individual counselling sessions. At group sessions, I made an announcement introducing the project and left contact information forms (Appendix M). Patients who were interested completed the form with their contact information and gave permission for me to contact them by phone or email.

Interviews. Interviews were scheduled for 60 minutes at a time and location that suited the participants. Interviews were done individually in iterative groups of five or six participants with analysis and revisions made to the questionnaire after each set of interviews. Five participants completed interviews with the first draft questionnaire (Round 1) and six completed interviews with the second draft questionnaire (Round 2).

I conducted the interviews in a FHT room that provided privacy. The purpose of the cognitive interview was explained and any questions were addressed. Participants provided written informed consent (Appendix N) and the sessions were digitally audio-recorded with permission. Round 1 interviews averaged 52 minutes with recordings ranging from 29-71 minutes. Round 2 interviews averaged 31 minutes with recordings ranging from 17-40 minutes.

The interviews were directed by a cognitive interviewing session guide (Appendix K) and were conducted using a combination of ‘think aloud’ techniques with scripted, spontaneous, concurrent, and retrospective probing as described by Willis (1999) and Beatty and Willis (2007). Participants were given an opportunity to practice the ‘think aloud’ technique. Then participants completed the patient experience questionnaire, reading the instructions and questions out loud. They talked out loud throughout the process of reaching their answer to the
question. There were predetermined probing questions based on predicted question problems as well as probes based on participant behaviours (Conrad & Blair, 2009). Participants were also asked general impressions of the questionnaire and whether they had any suggestions for adding or deleting specific questions. Notes were taken on specific aspects of the question wording and formatting on a copy of the questionnaire and additional comments were added to the data collection sheet (Appendix O). Participants completed the participant demographics questionnaire (Appendix L) at the end of the interview. As a token of appreciation, participants were given a $25 grocery gift card.

**Analysis of cognitive interviews.** Interviewer notes and digitally audio-recorded interviews were reviewed twice to ensure all relevant participant comments were noted. Interviews were not transcribed as we deemed the note-taking to be sufficient for analysis purposes. Participant comments and problems identified were aggregated by question and grouped by problem type using Willis’ coding classifications of issues (Table 4) as described in Buers et al. (2013). We reviewed the question problems aggregated in a CI report along with the patient experience dimension/sub-dimension (i.e. intended purpose/coverage of the questions), likely usefulness to quality improvement (QI), and suggestion of whether to keep, keep with revisions, or delete the question. We based modifications to the questionnaire wording and formatting on consensus.
Table 4: Willis’ coding system for classifying problems identified in cognitive interviewing.

<table>
<thead>
<tr>
<th>Problem category</th>
<th>Problem type</th>
</tr>
</thead>
</table>
| Clarify: problems with intent or meaning of a question | Wording  
Technical term  
Vague  
Lack of reference periods |
| Knowledge: likely to not know or have trouble remembering information | Knowledge  
Recall  
Computation |
| Assumptions: problems with assumptions or underlying logic | Inappropriate assumptions  
Assuming constant behaviour  
Double-barreled |
| Response categories: problems with the response categories | Missing  
Mismatch question-answer  
Vague  
Open-ended questions  
Overlapping  
Illogical order |
| Sensitivity: sensitive nature or wording/bias | Sensitive content (general)  
Sensitive wording (specific)  
Socially acceptable |
| Instructions | Introductions/instructions/explanations |
| Formatting | Layout or question order |
Chapter 5: Results

Results are presented chronologically and demonstrate the influences and decision-making throughout this questionnaire development project. Rate and rank survey results are presented first, followed by summarized discussion group results sent to participants for review, member-checking comments, a list of concepts we aimed to include in the first draft questionnaire, and modifications made as a result of cognitive interviews and expert review. Lastly, the results from discussion group post-hoc analysis are presented.

**Rate and rank survey.** The average importance ratings for the dimensions/sub-dimensions ranged from 1.3 to 2.2 on a scale of 1 to 5, where 1 was very important and 5 was not at all important. Results for each dimension/sub-dimension are presented in Table 5.

Table 5: Dimensions/sub-dimensions importance rating results.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Sub-dimension</th>
<th>Importance rating*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>average</td>
</tr>
<tr>
<td>Access</td>
<td>First contact accessibility</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
<td>Accommodation</td>
<td>2.2</td>
</tr>
<tr>
<td></td>
<td>Economic accessibility</td>
<td>1.8</td>
</tr>
<tr>
<td>Interpersonal communication</td>
<td>General communication</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td>Respectfulness</td>
<td>1.4</td>
</tr>
<tr>
<td></td>
<td>Shared decision-making</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Whole-person care</td>
<td>1.4</td>
</tr>
<tr>
<td>Continuity and coordination</td>
<td>Relational continuity</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>Informational continuity</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Coordination</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>Team functioning</td>
<td>1.4</td>
</tr>
<tr>
<td>Comprehensiveness of services</td>
<td>Services provided</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>Health promotion and primary prevention</td>
<td>1.6</td>
</tr>
<tr>
<td>Trust</td>
<td></td>
<td>1.5</td>
</tr>
<tr>
<td>Patient-reported impacts of care</td>
<td>Patient activation</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>Patient safety</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>Confidence in the PHC system</td>
<td>1.5</td>
</tr>
</tbody>
</table>

*1=very important, 5=not at all important
The overall top 5 ranked dimensions/sub-dimensions were: first-contact accessibility, trust, whole-person care, general communication, and respectfulness (Figure 2). This ranking did not change when the number of top 5 votes was tallied for each dimension/sub-dimension (Figure 3).

Figure 2: Dimensions/sub-dimensions ranking - Total Ranking Score

*Acc-First = access – first-contact accessibility; Acc-Accom = access – accommodation; Acc-Econ = access – economic accessibility; Comm-Gen = communication – general; Comm-Resp = communication – respectfulness; Comm-Shar = communication – shared decision-making; Comm-Whole = communication – whole person care; CC-Relat = continuity and coordination – relational continuity; CC-Info = continuity and coordination – informational continuity; CC-Coord = continuity and coordination – coordination; CC-Team = continuity and coordination – team functioning; Comp-Serv = comprehensiveness of services – services provided; Comp=PromoPrev = comprehensiveness of services – health promotion and primary prevention; Pt-Act = patient-reported impacts on care – patient activation; Pt-Safe = patient-reported impacts on care – patient safety; Pt-Conf = patient-reported impacts on care – confidence in the PHC system.
Figure 3: Dimension/sub-dimension ranking – Number of Top 5 Rankings

*Acc-First = access – first-contact accessibility; Acc-Accom = access – accommodation; Acc-Econ = access – economic accessibility; Comm-Gen = communication – general; Comm-Resp = communication – respectfulness; Comm-Share = communication – shared decision-making; Comm-Whole = communication – whole person care; CC-Relat = continuity and coordination – relational continuity; CC-Info = continuity and coordination – informational continuity; CC-Coord = continuity and coordination – coordination; CC-Team = continuity and coordination – team functioning; Comp-Serv = comprehensiveness of services – services provided; Comp=PromoPrev = comprehensiveness of services – health promotion and primary prevention; Pt-Act = patient-reported impacts on care – patient activation; Pt-Safe = patient-reported impacts on care – patient safety; Pt-Conf = patient-reported impacts on care – confidence in the PHC system.

Visually, these figures appear similar and indicate that the same dimensions/sub-dimensions are considered top priority when results are analyzed in slightly different ways. Dimensions/sub-dimensions ranked top 5 by at least one discussion group results in the addition of shared-decision making, economic accessibility, team functioning, patient activation, and informational continuity to the top ranked list.


**Discussion groups results summary.** The following results summary email was sent to interested participants for feedback:

**Rate and Rank results summary**

All 17 dimensions and sub-dimensions rated between 1.3-1.9 importance with the exception of access – accommodation which rated 2.2 (on a scale of 1 to 5, where 1 = very important and 5 = not at all important). This suggests that all of the sub-dimensions are important when considering the patient experience, and validates our use of this framework for our questionnaire development.

Ten sub-dimensions ranked in at least one group’s top five (# of groups ranking the sub-dimension in their top 5). In bold are the overall top 5 ranked sub-dimensions.

**Trust (5 groups)**
- Communication – General communication (4 groups)
- Access – First contact accessibility (3 groups)
- Communication – Whole-person care (3 groups)
- Communication – Respectfulness (2 groups)
- Access – Economic accessibility (2 groups)
- Communication – Shared decision-making (2 groups)
- Coordination & Continuity – Team functioning (2 groups)
- Patient reported outcomes – Patient activation (1 group)
- Coordination & Continuity – Informational continuity (1 group)

Selected discussion group highlights:
- Open-ended questions should be considered and not just at the end for additional comments.
- **First-contact accessibility** discussion often related to the marketing of nutrition/lifestyle services and of how the patient was able to access these services through their primary care offices.
- **Accommodation** issues came up in each group and the issues most noted were often different and specific to challenges in the communities of these FHTs. Of note, accommodation was not highly ranked to include in the questionnaire.
- Consistency of advice and messaging between different providers was highlighted in several groups and related to **general communication, informational continuity, and trust**.
- **Team functioning** was a sub-dimension that many felt would be difficult for patients to comment on as sometimes they are not aware of who is part of the team and that a well functioning team might not be ‘noticed’.
- Several groups discussed the need to find out if **services provided** were meeting patients’ needs, however thought it would be difficult for patients to know what services might meet their needs better.

This written summary was accompanied by a visual representation of the top 10 ranked dimensions/sub-dimensions. The top five are highlighted with square boxes and the next five have checkmarks beside them and are presented in Figure 4.
Figure 4: Ranking results sent to providers for member-checking.
**Member-checking.** All provider respondents expressed agreement with the top five ranked dimensions/sub-dimensions as demonstrated in the following three example quotes:

I agree with the top five rated responses and it is consistent with what I have experienced as a social worker. Trust and communication are key for patients.

After reviewing the material - I agree with the top 5 responses and there are no surprises that trust is at the forefront as well as communication.

I think that the Top 5 are not far off ones that we would have found important - as I recall trust was deemed to be almost the corner stone of any relationship as well as the broad domain of communication. It is not surprising therefore that three sub-domains of communication ranked in the top five - these also reflect ongoing work to improve the patient experience and access (top MOH priorities).

Some commented on dimensions/sub-dimensions they were surprised were not ranked higher, such as economic accessibility, patient-reported impacts on care, accommodation, and coordination. One participant replied:

It is interest[ing] to note the lesser importance attached to the types of services versus the more patient centric sub domains. It is also interesting to see less emphasis on continuity and coordination of services and information - something that we also seem to be encouraged to think about in terms of communication between FHT and community services.

(DG3 Participant)

**Concepts included in first draft questionnaire.** From the rate and rank survey results and the provider comments during discussion group sessions and member-checking responses, we drafted a set of concepts to include in the first draft of the questionnaire. We used the concepts presented in Table 6 as a starting place for selecting questions. For example, within the sub-dimension of first contact accessibility, providers mentioned that patients may have a poor awareness of the available lifestyle services and might not find out about them for many years. Some providers commented that if the lifestyle services were listed it would provide a form of marketing for currently available services.
“Services provided” had not been ranked highly, but given that this would be foundational to patient experience of lifestyle services, it was added. Attrition was a concept that did not come up specifically in the provider discussion groups, nor is it expressly included in the Wong and Haggerty framework of patient experience. This concept was included as it was deemed important for lifestyle services from personal experience and research group experts’ feedback. Other considerations from the provider feedback included using multiple open-ended response options.

Table 6: Concepts considered for the first questionnaire draft, by Wong and Haggerty dimension/sub-dimension.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Sub-dimension</th>
<th>Concepts considered for first draft</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>First contact accessibility</td>
<td>Marketing of services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wait times</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provider of choice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Timely access</td>
</tr>
<tr>
<td></td>
<td>Accommodation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Economic accessibility</td>
<td>Barriers to attending appointments</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Barriers to making changes</td>
</tr>
<tr>
<td>Interpersonal communication</td>
<td>General communication</td>
<td>Understandable communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enough time with providers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clear expectations of services provided</td>
</tr>
<tr>
<td></td>
<td>Respectfulness</td>
<td>Feeling heard</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feeling respected</td>
</tr>
<tr>
<td></td>
<td>Shared decision-making</td>
<td>Patients goals</td>
</tr>
<tr>
<td></td>
<td>Whole-person care</td>
<td>Joint discussion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Take whole person into consideration</td>
</tr>
<tr>
<td>Continuity and coordination</td>
<td>Relational continuity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Informational continuity</td>
<td>Patient information that was needed was available to all health care providers</td>
</tr>
<tr>
<td></td>
<td>Coordination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Team functioning</td>
<td>Consistent messaging</td>
</tr>
<tr>
<td>Comprehensiveness of services</td>
<td>Services provided</td>
<td>Meet needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Suggest improvements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Importance of service to patient</td>
</tr>
<tr>
<td></td>
<td>Health promotion and primary prevention</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Trust</td>
<td>Comfortable sharing personal information</td>
</tr>
<tr>
<td>Dimension</td>
<td>Sub-dimension</td>
<td>Concepts considered for first draft</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Trust provider</td>
<td>Trust information</td>
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<tr>
<td>Patient-reported impacts of care</td>
<td>Patient activation</td>
<td>Action on goals</td>
</tr>
<tr>
<td></td>
<td>Patient safety</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confidence in the PHC system</td>
<td></td>
</tr>
<tr>
<td>Additional concepts</td>
<td>Attraction</td>
<td></td>
</tr>
</tbody>
</table>
Cognitive interviews. Reports generated for each round of CI are included in Appendix P and document the question’s intention, expected usefulness to quality improvement, issues identified with CI, and my suggestions for changes. The six participants for Round 2 were asked their opinion about the length of the questionnaire and all indicated that the questionnaire was not too long.

May 2014 version questionnaire. The May 2014 version (Appendix Q) was modified based on the second round of CI sessions and consists of 23 questions. It focuses on evaluating one program or service in particular, and is customizable by the team that uses the questionnaire. There are 21 questions that have multiple choice options, 2 questions that are completely open ended, and 5 that include space to add extra comments. Table 7 presents the questions included in the first draft questionnaire compared to the questions in the May 2014 version questionnaire after both CI rounds, along with comments on some of the factors that prompted changes. In the first draft, both ‘lifestyle services’ and ‘nutrition and/or physical activity’ were used interchangeably. In the May 2014 version, all questions were changed to ‘nutrition and/or physical activity’ to use consistent and more specific language. Wording was also made consistent to refer to the health care providers as ‘team members’. The questions include concepts from the dimensions/sub-dimensions of first-contact accessibility, economic accessibility, general communication, respectfulness, shared decision-making, whole-person care, team functioning, services provided, trust, and patient activation. There is also one question about attrition.
Table 7: Comparison of questions from first draft and May 2014 version questionnaires.

<table>
<thead>
<tr>
<th>Dimensions/sub-dimensions</th>
<th>First draft</th>
<th>May 2014 version</th>
<th>Comments</th>
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<tbody>
<tr>
<td>First-contact accessibility</td>
<td>(1) What lifestyle services have you accessed to help you make changes to your nutrition and/or physical activity(^a). (2) How did you find out about this service? (3) How did you access this service? (4) How long did you wait from the time you were referred to the time you had your first appointment? (9) How often were you able to choose who you met with to help you with changes to your nutrition and/or physical activity?(^b). (10) Were you able to talk with a team member about your nutrition and/or physical activity when you wanted to?(^c).</td>
<td>(1) How did you find out about this service? (2) How did you access this service? (4) How long did you wait from the time you were referred to the time you had your first appointment? (8) Were you able to contact a team member about your nutrition and/or physical activity when you wanted to?(^c).</td>
<td>a. Removal of question as it was confusing for patients throughout questionnaire to consider more than one service. b. Removal of provider of choice question as many patients indicated that there wasn’t choice, nor would they expect there to be a choice of which RD they see for example. c. “Talk to” change to “contact” to account for non-verbal forms of communication E.g. email.</td>
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<tr>
<td>Economic accessibility</td>
<td>(11) How often did you find it difficult to get to lifestyle service appointments or programs because of the additional costs or time involved? (baby-sitting, parking, transportation, etc)(^d).</td>
<td>(9) Were there times when you found it difficult to get to nutrition and/or physical activity appointments because of the additional costs or time it involved (e.g. childcare, parking, transportation, work schedule, other commitments)?(^d).</td>
<td>d. Initial question modified CIHI original to account for frequency related response options. Reversion to original as “how often did you find” seemed to make reading and answering difficult for patients. Added time related examples.</td>
</tr>
<tr>
<td>Dimensions/sub-dimensions</td>
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<td>May 2014 version</td>
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<tr>
<td>General communication</td>
<td>(7) Did you know what to expect from the lifestyle services program in terms of how many appointments you would have, what you would learn, and the amount of support you would be offered? (12) How often did the team members explain things to you in a way that you clearly understood?</td>
<td>(6) Did you know what to expect from the nutrition and/or physical activity services in terms of how many appointments you would have, what you would learn, and the amount of support you would be offered? (10) How often did the team members explain things to you in a way that you clearly understood?</td>
<td>e. Patients reported all three questions very similar, decision made to include one only.</td>
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<tr>
<td>Respectfulness</td>
<td>(16) How often did the team treat you with courtesy and respect?</td>
<td>(12) How often did the team members treat you with courtesy and respect?</td>
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<tr>
<td>Shared decision-making</td>
<td>(18) Were you involved in setting lifestyle goals that address the health issues that matter to you? e. (19) Were you supported in making realistic lifestyle changes that you could carry out in your daily life? e. (20) Did you and your team work out a lifestyle change plan together? e.</td>
<td>(17) Were you involved in setting nutrition and/or physical activity goals to address the health issues that matter to you? e.</td>
<td></td>
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<tr>
<td>Whole person care</td>
<td>(17) Did the team consider your personal situation (lifestyle, income, traditions, and culture) when making nutrition and/or physical activity recommendations for you?</td>
<td>(13) Did the team members consider your personal situation (lifestyle, income, traditions, and culture) when making nutrition and/or physical activity recommendations for you?</td>
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| Informational continuity  | (14) How often did you have to repeat information that should be in your medical record?[^f]  
(22) How often were there times when the person you were seeing did not know about lifestyle changes in your plan that another person within your team recommended?[^f]. | Omitted[^f]      | f. Questions seemed to confuse participants. They wouldn’t have expected informational continuity. May have been due to use of participants who had attended centralized group services, not in their family doctor’s office. |
| Team function             | (23) How often were you told different things (that didn’t make sense together) about your nutrition and/or physical activity? | (15) How often were you told different things (that didn't make sense together) about nutrition and/or physical activity? |          |
| Services provided         | (13) How would you describe the amount of time you had with team members to support your lifestyle changes?[^g]  
(25) In the last 12 months, has your team provided the information and support you need to make changes to your nutrition and/or physical activity?[^h]  
(28) How would you rate the importance of the nutrition and/or physical activity services you received to your overall health care?[^i]  
(29) Are there other nutrition and/or physical activity services you would like offered by your team?[^j]. | (3) How would you rate the importance of this service to your health?[^i]  
(7) How would you describe the program length to support your lifestyle changes?[^g]  
(16) Have the team members provided the information and support you need to make changes to your nutrition and/or physical activity?[^h]  
(23) Are there services that you think should be added, removed, or changed?[^j]. | g. Patients consistently interpreted time as single sessions, changed question to be more clearly about program length.  
h. Removal of timeframe as questionnaire now refers to specific service.  
i. “Overall health care” not well understood, changed to be about one service in particular and to health instead of health care in general.  
j. Combined open ended questions and reduced perceived duplicate concepts. |
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<tr>
<td></td>
<td>(30) What else would improve the lifestyle services offered through this clinic?</td>
<td></td>
<td>k. Changed from a question where respondents were guessing at what the provider knows to a question that is more about the respondent’s confidence in the information.</td>
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<tr>
<td>Trust</td>
<td>(15) Were you comfortable sharing personal information with the team?</td>
<td>(11) Were you comfortable sharing personal information with the team members?</td>
<td>k. Changed from a question where respondents were guessing at what the provider knows to a question that is more about the respondent’s confidence in the information.</td>
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<td></td>
<td>(21) How often did the people you meet with about nutrition and/or physical activity know what they were talking about?</td>
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<td></td>
<td></td>
<td>(14) Did you have confidence in the information about nutrition and/or physical activity that the team members gave you?</td>
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<tr>
<td>Patient activation</td>
<td>(24) Were there times when you did not try the suggested lifestyle changes because something got in the way?</td>
<td>(18) How confident are you that you can maintain the changes in your nutrition?</td>
<td>l. Separated out nutrition and physical activity for both barriers and confidence in maintaining changes as may have different responses to each part that would be useful to identify.</td>
</tr>
<tr>
<td></td>
<td>(26) How confident are you that you can maintain the changes in your health habits like nutrition and/or physical activity?</td>
<td>(19) How confident are you that you can maintain the changes in your physical activity?</td>
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<td></td>
<td>(27) How has working with the team on nutrition and/or physical activity helped you better manage your health?</td>
<td>(20) Were there times when you did not try the suggested nutrition changes because something got in the way?</td>
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<tr>
<td></td>
<td></td>
<td>(21) Were there times when you did not try the suggested physical activity changes because something got in the way?</td>
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<tr>
<td></td>
<td></td>
<td>(22) How has working with the team members on nutrition and/or physical activity helped you better manage your health?</td>
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<tr>
<td>Other (attrition)</td>
<td>(5) Did these lifestyle services have a set program? For example a specific number of visits or length of time? ( m ). (6) Did you stop attending before the program finished? (8) Did you stop attending nutrition and/or physical activity appointments before achieving your goals? ( m ).</td>
<td>(5) Did you stop attending before the program finished?</td>
<td>m. Simplified and eliminated the skip sequencing in the questionnaire. Original had intention of asking more questions of those who stopped program early.</td>
</tr>
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</table>
**Health care provider discussion group post hoc analysis.** The dimensions and sub-dimensions were generally well understood by participants and there are many examples of discussion that fit well with the definitions within the framework. In Table 8, the definitions are paired with examples of the main concepts mentioned and quotes from the discussion group participants. There were some exceptions with differences or aspects of the framework that didn’t quite fit for providers.

Within comprehensiveness of services, some participants did not see the need to separate out the two sub-dimensions, services provided and health promotion and primary prevention:

> I would see services provided and health -- I would see both of these -- I’m having a hard time separating them. I’m seeing them as one… so the services I’m giving are more health promotion or preventing further complications down the line rather than kind of that immediate tertiary care… (DG2 Participant)

The concept of equity wasn’t obvious in the framework and was identified in one group as an important aspect to capture:

> What about equity? So all patients whether they have a home or are homeless or handicapped have equitable service, the same as your typical patient. Equity you know whether it be a child or have a horse and buggy…how can we meet those needs. (DG4 Participant)

For some participants, there were dimensions of the framework that overlapped substantially such as with access and comprehensiveness of services, trust with all other dimensions, whole-person care with team-functioning, and accommodation with patient safety.

Access overlapped with concepts of the comprehensiveness of services in several discussion groups. Access to the different team members was seen by some as an issue of getting first-contact and ongoing care as well as accommodation within the services provided.

> P1:…so the whole thing about behaviour, activation, self care, …and I do a lot of work in supporting people in chronic disease management as well so that whole thing around lifestyle, exercise, nutrition, self care is important. I
kind of feel that question should be more specific but right off the top of my head it’s that thing about being supported by other health care professionals.

P2: Does that fall under your comprehensiveness of services part?...

[...moderator comments]
P1: ...and not access?

[...moderator comments]
P2: ...I’m wondering if that question might be more appropriate in comprehensive services.
P1: So for example if one of our dietitians is … working with a patient who has anorexia nervosa or is being assessed for bariatric surgery, then it’s very important to have sort of a time frame I mean for me to be seeing them at the same time in a timely way. So access to me – that’s what I meant by access to other health care professionals.
P2: So they’re getting all of the relevant care. They’re getting access to all not just the gateway person who is bringing them in at the door right? I get where you’re going. (DG5 Participants)

When I think about accessibility I think about like if they’re booked in terms of their urgency, but also ongoing appointments and if that was booked to their satisfaction so sometimes there’s limitations on the number of visits people can have which does not necessarily meet their initial goals that they’re coming for or initial needs so that perhaps like their mental health problems are more chronic than what we’re actually able to provide and so I think about accessibility in those terms too. (DG4 Participant)

I think there’s an accommodation piece too in terms of comprehensiveness of service because I think there’s some accommodations we make in provision of those services. (DG1 Participant)

For some participants, trust was connected to all other dimensions, intertwined, and impacting on all aspects of the patients’ experiences.

So you could, you could attribute trust to every single—It ties in globally… I think trust ties into every single of these categories. …Every single one. (DG1 Participant)

They trust us when we give them choice, flexibility, respect, right? (DG1 Participant)

Like, so then we as a team are building on one person’s trusting relationship to then be able to offer different services (DG2 Participant)

I think there’s trust within health care providers, right? So I think, for example different health care providers will tell the patient something
different and they’re not sure who to believe, so a physician might give dietary advice. And then we come and we’ll say “Well no, no, you should do it this way” And there’s also, there’s the hierarchy …they may choose the physician’s because that’s their long-standing relationship and the trust factor is there with them over what we say even though we would be the experts, so I think there’s always a disconnect, often a disconnect between health care providers on who to trust for the information. (DG1 Participant)

Whole person care was related to team functioning or a result of good team functioning for some participants:

P1: Does your provider know are they aware that you’re involved with other programs within the family health team?
P2: That’s a good one. -- And then that begs the question because there’s potential for everyone to pick that person apart according to their specialty area so you know, did you feel that even though you were looked after by members of a team did you still feel that you were treated in sort of like in a holistic way as opposed to everyone getting a piece of you.
P3: That the team was working together –
P2: yeah, to provide a holistic care vs specialized care.
P4: That might be under team functioning and could also be under the whole person care. (DG5 Participants)

Access (accommodation) was linked with patient safety by participants in one group:

P1: Just Patient Safety? I thought of something else. The physical accommodation piece which kind of goes into Accommodation too, so safety in terms of, like I’m thinking, you know, bariatric chairs in a waiting room, you know, getting, being able to get in through, you know, your--- the walker in the room, in your office with chairs and that it’s not all and -- like strollers are an issue too, and that kind of thing so I think --
P2: Physical access.
P1: Yeah, it kind of goes with Accommodation but it’s also Patient Safety because if, if, you know, if a patient sits on a chair and it doesn’t hold their weight then that’s Patient Safety. You know, if we don’t have accommodation for those patients. (DG1 Participants)

There is also a hint of why patient activation did not rank highly by providers with the following comment from participants in one group:

P1: I think that’s kind of at the bottom of the list, I’d say, because you can’t have patient activation without trust or communication or team function –
P2: Or accessibility. (DG1 Participants)
Overall, the results of the content analysis confirmed that providers were able to easily describe questions or concepts to address the dimensions/sub-dimensions. However, there were some that seemed to overlap in conceptualization, such as with access and comprehensiveness of services, trust with all other dimensions, whole-person care with team-functioning, and accommodation with patient safety. These results provide insight into the rate and rank results and will be further explored within the discussion section.
Table 8: Comparison of Wong and Haggerty dimension/sub-dimension definitions with main concepts and quotes from discussion groups.

<table>
<thead>
<tr>
<th>Dimension/Sub-dimension</th>
<th>Definition</th>
<th>Main concepts</th>
<th>Example quotes</th>
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<tbody>
<tr>
<td>First contact accessibility</td>
<td>The ability to obtain patient-initiated needed care (including advice and support) from the provider of choice within a time frame appropriate to the urgency of the problem.</td>
<td>Similar concepts came out in terms of time frame (wait times), though family doctor was seen as gatekeeper and not just patient-initiated access to lifestyle services.</td>
<td>My wait list has been anywhere between one week and 12 weeks in my time here so I think ‘how long did you wait for your first appointment’ is an important question. It indicates to me how efficient I am. (DG5 Participant)</td>
</tr>
<tr>
<td>Economic accessibility</td>
<td>The extent to which direct and indirect costs relate to care impeded decisions to access needed care or continue recommended care.</td>
<td>Barriers to attending appointments (transportation access and affordability, childcare) as well as barriers to following through on lifestyle change recommendations (food and activity costs).</td>
<td>Well, I would say that - I’m the dietitian - and economic accessibility is a huge factor with both access to fitness facilities and food. I hear about that pretty much all day, every day, about how people are really limited by income, so probably that kind of jumped out to me. (DG2 Participant)</td>
</tr>
<tr>
<td>General communication</td>
<td>The ability of the provider to elicit and understand patient concerns, and to explain health and health care issues.</td>
<td>Getting patient to open up and be honest. Providing information about health and services offered (e.g. Lifestyle services). Importance of the patient feeling heard and validated.</td>
<td>I think a patient really first and foremost needs to feel they have actually been heard (DG1 Participant)</td>
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<tr>
<td>Dimension/Sub-dimension</td>
<td>Definition</td>
<td>Main concepts</td>
<td>Example quotes</td>
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<tr>
<td>Respectfulness</td>
<td>The ability of the primary care organization and practitioners to provide care that meets the expectations of users about how people should be treated, such as regard for dignity and provision of adequate privacy.</td>
<td>Addressing patient important goals, privacy of information respected and shared appropriately.</td>
<td>And did you feel that person would respect your personal information and share only as need? (DG5 Participant)</td>
</tr>
<tr>
<td>Shared decision-making</td>
<td>The extent to which patients are involved in making decisions about their treatment.</td>
<td>Making goals that are informed, patient-directed, and sharing these goals amongst professionals.</td>
<td>Questions around whether they’re provided with enough or appropriate information to make an accurate decision and sharing that decision within the process. If you’re not provided with the information then you can’t really make an informed consent or informed decision. (DG5 Participant)</td>
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<td>If it’s not shared decision-making with the client, those aren’t their goals. And so I’m usually kind of quick to jump the gun and say, “These should be your goals,” but it’s like taking a step back and realizing if I make the goals, they’re not going to really agree with them. So I think that’s really key there, as well as with the Respectfulness. If you’re not respectful to a patient… (DG2 Participant)</td>
</tr>
<tr>
<td>Whole-person care</td>
<td>The extent to which providers address the physical, emotional and social aspects of a patient’s health and consider the community context in their care.</td>
<td>Looking at mental, physical, overall well-being, ‘holistically’.</td>
<td>And well, communication plays in it too, but the Whole-person Care is really, comes, the first thing that comes to mind is just the whole aspect of being a family health team in primary care. We look at both mental, physical, and the overall well-being of an individual (DG2 Participant)</td>
</tr>
<tr>
<td>Dimension/Sub -dimension</td>
<td>Definition</td>
<td>Main concepts</td>
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| Team functioning         | The ability of primary health care providers to work effectively as a collaborative team to manage and deliver quality patient care. | Consistent messaging, team communication and togetherness. | …were they told the same information from each person along the way, or did they get into the office, the doctor told them one thing, the nurse told them something else and then the receptionist told them something else and then they get home and they go ‘well I don’t know what I’m supposed to do now because I’ve been told so many different things’. (DG4 Participant)  

I’d say Team Functioning -- when I think of that, I think of everyone coming together and discussing -- a team meeting for example. (DG2 Participant)  

Or even if you see different dietitians are they saying the same thing. To use an example. Someone says its cholesterol problems and someone else says no no no that’s not the problem at all. To make sure we’re all on the same page…was the information consistent that was being delivered? (DG5 Participant) |
| Services provided        | The provision, either directly or indirectly, of a full range of services to meet patients’ health care needs. This includes health promotion, prevention, diagnosis and treatment of common conditions, referral to other clinicians, management of chronic conditions, rehabilitation, palliative care and, in some models, social services. | Meeting the needs of the patients and quality vs. quantity. | Well it’s kind of like the question they ask at Walmart – did you find everything you were looking for today? (DG5 Participant)  

R1: Or do you, or do you clarify what you mean by comprehensiveness of services? Are you talking about different services or are you talking about the same service?...  

R2: It’s almost like quality versus quantity of service…  

… they don’t know what was comprehensive, but did it meet their needs? And that’s what we want. So if it met their needs, perfect. (DG1 Participants) |
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<tr>
<td>Trust</td>
<td>An expectation that the other person will behave in a way that is beneficial and that allows for risks to be taken based on this expectation. For example, patient trust in the physician provides a basis for taking the risk of sharing personal information.</td>
<td>Various types and levels of trust related to provider, information/advice, and intervention.</td>
<td>There’s so many different levels of it. Like trust with who? with the nurse, with other patients, with reception, staff, doctors. (DG4 Participant) … did you have confidence in the competence of your health care provider so that you felt that the information you were getting that it was explained, that there was a good basis and that it was competent advice? (DG5 Participant) Like to me, I would evaluate trust, if someone told me they ate a whole cake last night. To me, that’s a sign that they’re: “Okay, this is a safe place. This is the dietitian but I can still admit that I am struggling.” So I evaluate trust in little things like that, or if they start bringing in, you know personal issues in their life that’s affecting what I’m trying to counsel on, “Okay they’re trusting me with that information that’s related, but, you know, not required of them to tell me.” (DG2 Participant)</td>
</tr>
<tr>
<td>Patient activation</td>
<td>Patient’s ability or readiness to engage in health behaviours that will maintain or improve their health status.</td>
<td>Readiness for change, confidence in achieving the goal, and most helpful to patient.</td>
<td>R1: Whether they’ve developed skills or whether they gained more knowledge along the way, whether they’ve incorporated anything that they’ve learned into what they’re -- into how they’re living now. Like, whether they’ve made dietary changes? Whether they’ve learned how to read a food label, etcetera. It could be different skills but -- just the idea -- R2: Yeah. “Do you have new skills and are you using them? Are they helpful?” (DG2 Participants) R: Well you’d have to phrase it in terms of-- well they wouldn’t know the stages but they would certainly know as you say they know whether “I’m ready to go and I can do this”. (DG5) So, having some kind of a catch-all question that might elicit another zone, but just asking people, “Out of all the experiences that you’ve had with whatever you’re evaluating, what was the most helpful for you?” And I think having a question like that might help us really understand what other people are finding helpful. (DG2)</td>
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Chapter 6: Discussion

This development project makes several unique contributions to the literature. We developed a new questionnaire to assess the patient experience of lifestyle services to fill a void in quality improvement efforts. We used a primary care health services framework that differed from previous nutrition services evaluation tools and explored the fit of this framework with health care provider feedback. Finally, we positioned the questionnaire to reflect the team-based nature of lifestyle services in primary care. This differs from the primary care and nutrition service provider specific evaluation tools currently available.

In this discussion section, I will reflect on the contributions of the health care provider discussion groups to this project and the interpretation of the patient experience framework we used. Then I will discuss the questionnaire that we produced to compare our work to published primary care patient experience and nutrition service questionnaires, expand on the key concepts in the May 2014 version, and the process we used to make revisions. Finally, I will connect our work to the larger quality improvement efforts and propose next steps and future research needs.

Health Care Provider Involvement

This project demonstrates the use of the latest Canadian primary care context patient experience framework as it can be applied to a particular sub-set of primary care services. To our knowledge, this is the first use of Wong and Haggerty’s framework applied to a specific service for patient experience evaluation. We brought this back to front line, non-research community primary healthcare providers and found that it was generally understood and applicable in the context of conceptualizing patient experience of a specific service (nutrition and/or physical activity, i.e. lifestyle services) in primary care. We used member-checking of the provider rate and rank results prior to moving to the next stage of questionnaire development in order to
confirm with health care providers that their opinions were accurately reflected prior to starting the first draft of the questionnaire.

Involvement of front-line providers to prioritize dimensions to include in a lifestyle service evaluation tool is relatively unique. Hauchecorne, Barr, and Sork (1994) were advised by an expert panel of five RDs and one social worker and both Ferguson et al. (2001) and Spikmans et al. (2003) interviewed providers. It is unclear if prioritization on the relative value of the different aspects was part of the feedback from providers in these studies. It appears that in these studies providers were consulted for concepts to include, but no studies were found where providers rate the importance or rank priority of the dimensions to evaluate in a lifestyle service context. We could have included questions from all of the dimensions/sub-dimensions instead of prioritizing and eliminating some but we intuited early in the project that reducing the scope would be preferable in order to limit the number of questions. Questionnaire length will be discussed further under the questionnaire development process.

Participants in the provider discussion groups seemed to generally understand the Wong and Haggerty framework. They mentioned concepts applicable to the dimension/sub-dimension definitions and gave examples of lifestyle service questions that fit within the dimensions. All dimensions/sub-dimensions were rated of high importance, which can be interpreted as an endorsement of the framework. With the exception of equity, there were no missing dimensions or aspects identified. In both the Pan-Canadian Primary Health Care Indicators (CIHI, 2006) and Ontario’s Primary Care Performance Measurement Framework (Ontario primary care performance measurement steering committee, 2013), equity is an underpinning concept to be included within all indicator areas. Equity in this context of lifestyle services may relate especially to access, communication, and patient activation for those who are disadvantaged.
Disadvantaged patients may have challenges with booking and getting to appointments, developing health literacy, and affording treatment costs (Glazier, 2007). We did not specifically address or assess equity within our project and more work is needed to determine how best to do this in the context of a lifestyle services patient experience questionnaire. It may be, as Haggerty et al. (2007) suggest, that equity is more inferred from outcomes rather than the subject of measurement.

There were some aspects of the application of this framework to lifestyle services that identify a need for further evaluation or development of the framework. Participants identified dimensions and sub-dimensions that overlapped, which can pose problems for interpretation of questions and evaluation of the specific sub-dimensions. Haggerty et al. (2007) also noted overlap in their expert consensus work of creating operational definitions of primary care attributes, which was one of the foundational pieces influencing the Wong and Haggerty patient experience framework. I will discuss two of the identified overlaps: access overlapping with services provided, and trust overlapping with multiple other dimensions.

The overlap of access and services provided may be related to the use of a primary care framework that views access as access to the primary care provider. Team members of lifestyle services may be these primary care providers (family doctor or nurse practitioner), but are more likely to be an RD, exercise expert, or health promoter. This highlights one of the challenges of using a general primary care framework for a service specific purpose. In a sense, when looking at lifestyle services (a service provided after accessing primary care), there is also an access piece. Knowing about it, through effective marketing, and being able to access it in a time-sensitive manner is similar to first-contact accessibility. Reducing barriers to follow through on accessing services and continued participation is similar to economic accessibility and
accommodation. This conceptualization of lifestyle services as a second ‘level’ of services provided may contribute to the overlap of these two aspects of the framework. Adapting the framework and definitions to a lifestyle service context may be helpful in the future.

Providers in our discussion groups talked about trust as it connected to all other dimensions, as a concept with different types and levels depending on person and situation. They talked about trust relating to being given choice in who they see (access), resulting from being treated with respect, as well as having trust in the interventions (services provided), and in the providers to act on their behalf to coordinate care and to provide safe care. Trust as a separate dimension may then be challenging to measure or isolate. When comparing primary care patient experience surveys, Beaulieu et al. (2011) conceptualized trust as a result of interpersonal communication rather than a component of it. It is thought that health care providers build rapport and trust through skillful communication (Steinecke & College of Dietitians of Ontario, 2013). The inter-connectedness of trust to the other dimensions discussed in the groups may explain the high prioritization ranking by providers.

The top ranked dimensions/sub-dimensions seemed fairly similar across groups, despite having three different facilitators who potentially could have each influenced the discussion differently. The ranking results provided some rationale for inclusion and exclusion of sub-dimensions in the questionnaire. We are not confident that our primary care provider feedback is fully representative of primary care teams. Participants were primarily nurses, administrative staff, and RDs. One provider category that was completely missing from the discussion groups was family doctors. We had no control over the make-up of the provider groups. FHT executive directors were asked to gather a diverse group of providers, and it is unclear whether family doctors were omitted in the invitation or whether they just chose not to participate. It is hard to
know how the results would have differed had family doctors been included in the groups, but it is reasonable to expect that feedback may have been different from family doctors. We also could have included other models of primary care in discussion groups or member-checking to increase the variety of feedback and increase the likelihood of a generic tool development. We limited this project to recruiting participants in the FHT model. We did this for several reasons. FHTs are one of the largest interdisciplinary team models in our local area, they run diverse lifestyle-related programs, and they are a relatively easy group to contact for recruitment purposes.

**Resulting Questionnaire**

**Development process.** Best practices in the art of new questionnaire development tend to be fairly general and we decided to start with a previously developed theoretical framework. This was very helpful as lifestyle programming in primary care is an emerging area of practice. The process that we chose in this questionnaire development involved determining concepts to include based on a theoretical framework and provider input, adaptation of existing questions, and pilot-testing with the target population. This is a similar process as described by Wong and Haggerty (2013) in the development of the CIHI patient experience survey. With their new pan-Canadian questionnaire released in April 2013, all primary health care expert derived dimensions/sub-dimensions were included. Questions were adapted from validated and publicly-available primary care surveys. The resulting questionnaire went through CI with patients and content review from members of the primary health care research community. No details were provided for the process or numbers involved in CI or content review. Farmanova, Grenier, and Chomienne (2013) also described their process for developing a patient experience questionnaire specific to mental health services in FHTs (MHS-FHT). They used the Canadian Health
Indicators Framework (2004 CIHI) for questionnaire item development and tested their questionnaire with 10 patients using cognitive debriefing. Participants were sent the questionnaire in the mail and provided written comments back to the researchers related to question wording clarity and complexity, question order, and questionnaire flow and length. These two examples demonstrate that we have met an acceptable standard for initial questionnaire development and we are ready for trialing in a lifestyle program - understanding that further testing and revisions will continue to improve the measure.

**Framework.** There are no frameworks specific to patient experience of primary care lifestyle services. Surveys related to nutrition services or lifestyle counselling use a variety of strategies to determine question coverage. Hauchecorne et al.’s (1994) work to develop a tool to evaluate the impacts of nutrition counselling on patient’s health and well-being adapted Bopp’s Value-Added Ambulatory Encounter framework to present a Value of Nutrition Education framework and covered the following aspects: improved physical well-being, fulfillment of interpersonal psychological need, reduction of uncertainty, control, and accessibility. Spikmans et al.’s (2003) work to develop a tool to assess determinants of non-attendance of nutrition appointments extended the Health Belief Model with factors they identified as predictors of attendance from interviews with health care providers and patients. Trudeau and Dube’s (1995) work to develop a tool to assess patient satisfaction with diet counselling used Mason’s four components of diet counselling: knowledge, cognitive communication skills, affective communication skills, and facilitation skills. Ferguson et al. (2001) used a literature search to identify seven dimensions of patient satisfaction with clinical nutrition services: technical competence, facilitation skills, presentation skills, interpersonal skills, nutritional supplements, educational material, and perceived benefit of nutrition services. Vivanti et al. (2007) adapted
their patient satisfaction survey from Ferguson et al.’s work and found their questionnaire had four factors: interpersonal skills and staff presentations, perceived health benefits of nutrition, written materials, and fulfilled expectations. Marshall et al. (2011) and Otero-Sabogal et al. (2010) do not describe how they determined which questions to include in their tools.

There are some connections from these nutrition service evaluation dimensions to those in the Wong and Haggerty’s patient experience of primary health care framework. For example, communication skills and interpersonal skills fit within interpersonal communication; control, improved physical well-being, and perceived benefit of nutrition services fit within patient-reported impacts on care; educational materials and nutritional supplements might fit within services provided.

We decided to use a primary care health services oriented framework instead of previously used nutrition counselling/services or behaviour change frameworks. We did this to position our work in the broader national primary care patient experience evaluation and quality improvement context. By using the same language as our colleagues in primary care, we produced a questionnaire that can be added to the existing general practice patient experience questionnaire. The risk in using the Wong and Haggerty framework is that there may be important aspects of lifestyle services that are not adequately covered. One example of this is the concept of attrition, or ‘no shows’ and cancellations. Attrition is a predictor of outcomes in lifestyle programs (Stubbs et al., 2011). Attrition rates of 10-80% have been seen in research involving lifestyle interventions (Moroshko, Brennan, & O’Brien, 2011), and rates of no show or cancellation in primary care nutrition practice may range from 30-50% (Tracy Hussey, personal communication, 2014). This is an aspect that is not evident in the Wong and Haggerty framework.
It is important to note that competing demands of a short self-administered questionnaire versus consideration of all important aspects of the patient experience of lifestyle services creates competing priorities. Provider rate and rank results indicate that all dimensions were considered important and thus it may have been difficult to narrow down or eliminate dimensions to include. However, three clear priorities emerged: access, interpersonal communication, and trust. Sub-dimensions of team functioning, services provided, patient activation, and attrition were included in the May 2014 version questionnaire based on provider feedback and expert opinion. I will discuss each of these dimensions/sub-dimensions to elaborate on some of the key concepts that were included.

**Access.** Access is one of the three components of the Triple Aim (Institute for Healthcare Improvement, 2013)- better access, better care, lower cost - which has been adopted by many in health care leadership in Canada. First Ministers have set targets for the percentage of Canadians who have access to interdisciplinary primary care (Health Canada, 2006), and there is an expectation that increased access to interdisciplinary teams would result in a substantial return on investment in the range of $100s of millions per year (Dinh & Bounajm, 2013).

Providers in our discussion groups prioritized first-contact accessibility (top ranked sub-dimension) and economic accessibility as aspects to include in the questionnaire of lifestyle services. Within first-contact accessibility, providers also included the concept of knowing about, or marketing, the services as patients would have to become aware of the services available before accessing them. We included a question about how patients found out about the service and another question about who referred them to the service. Ideally, we would want to see a higher percentage of patients self-referring and also be able to identify those providers who could be referring more often.
Timely access may be especially important for behaviour change, such as nutrition and physical activity, in order to take advantage of a patient’s motivation to change and increase their promotion of the program to others (VanWormer, Martinez, Cosentino, & Pronk, 2010). We included a question about the wait time from referral to the time patients had their first appointment. This is to allow teams to benchmark wait times and identify if wait times could be optimized.

Providers from all discussion groups talked about the relationship of economic accessibility to lifestyle services. They recognized the many financial barriers that people face not only with accessing services but also with following through on lifestyle change. A recent study of Canadian Community Health Survey data looked at barriers to health behaviour change (Haberman, Brauer, Dwyer, & Edwards, 2014). The most often cited barrier was ‘lack of will power’ by 33.6% of the respondents. Work schedule and family responsibilities could be interpreted as time-related barriers and was reported by 14% and 7%, respectively. Only 2.7% of respondents reported that their barrier to behaviour change was cost. There seems to be a difference in observations of providers and what Canadians report related to economic accessibility and financial barriers to health behavior change and this may be worth further exploration. Keeping economic and other barriers in mind we included a question on barriers to attending appointments which includes concepts of both time and monetary costs in the examples listed. This was intentionally a double-barreled question as we felt it was not important to differentiate. Both act as barriers to access and would result in patients not attending services. The hope is that if barriers to access are frequently reported, then the open-ended response option of this question would provide further clues or would trigger more information collection with other methods.
**Interpersonal communication.** Patients prioritize the importance of communication with their primary care provider very highly (Grol et al., 1999) and providers in our discussion groups ranked all four interpersonal communication sub-dimensions within the top six dimensions/sub-dimensions. All nutrition and lifestyle surveys reviewed included questions related to general communication. If patients feel heard they have a more positive nutrition counselling experience (Hancock, Bonner, Hollingdale, & Madden, 2012). Shared goal setting and expectations are important for preventing attrition (Delahanty, 2010), and if patients do not feel their whole-person is taken into consideration, they may not feel the advice or information is relevant to them (Hancock et al., 2012). Interpersonal communication is currently not being evaluated from a team-based perspective in primary care and Beaulieu et al. (2011) identified this as an area that needs more research. We included questions on all four interpersonal communication sub-dimensions and focused on the concepts of clear and tailored information, shared goals, and feeling respected.

**Trust.** In the primary care setting, where interdisciplinary team care is relatively new, the patient’s trust in the team is established from the trust between the patient and family doctor (Rosser, Colwill, Kasperski, & Wilson, 2011). Some physicians may be hesitant or uncomfortable asking patients about trust (Brauer et al., 2012), especially as it is generally considered a difficult aspect of the patient-provider relationship to improve if damaged. Providers in our discussion group identified that there are many different types and levels of trust, with respect to the various providers, the information provided, or to tasks needing to be completed. Sharing personal information with a provider can be interpreted as a sign of trust (Steinecke & College of Dietitians of Ontario, 2013). We tried to narrow down the trust concept to aspects that are specific, rather than asking about trust of a provider or the whole team. We
chose questions related to trust of the information and comfort in sharing personal information. If trust is identified as an issue, teams would need to explore what would improve patients’ trust in these areas.

**Team functioning.** Providers in our discussion groups commented that patients may not be witness to the team functioning in their FHT. Patients are most comfortable evaluating what they witness or experience (Haggerty et al., 2011) so it may not be appropriate to ask about team functioning directly. The concept of providing consistent messaging from different team members came up in several discussion groups and may be considered a sign of good team functioning. Patients find it reassuring to hear the same messages from different people and conversely get confused when they hear conflicting messages (Hancock et al., 2012). We included a question on team functioning related to consistent messaging from different providers.

**Services provided.** Hancock et al. (2012) reported on patient experiences of nutrition counselling and identified the importance of providing sufficient information, as long as it is adapted to the patient’s situation, as well as sufficient supports for patients to change behaviour. From our discussion group providers’ comments, it seemed as if the type and quality of services provided didn’t matter if patients were having poor experiences in the other dimensions. Most of the other dimensions/sub-dimensions were prioritized above services provided. Despite this we decided to add the services provided sub-dimension as this is a service-specific questionnaire. We chose questions that were related to more general aspects of the services: the service importance to the patient, the length of the program/service, and the support provided. We also included space for patients to comment on service areas that could be improved.

**Patient activation.** Ultimately the goal of lifestyle services is to support people in making changes to their eating habits and physical activity for health promotion, disease
prevention, and management of chronic conditions for which modifiable lifestyle factors play a role. We included questions related to patients’ confidence in maintaining changes, barriers to making suggested changes, and impact of lifestyle services on management of health. If patient activation questions identify that improvements are needed, then the teams could explore alternative strategies for shared goal setting, confidence building, and developing services which patients report have positive impacts on their health.

**Attrition.** We included a question that aimed to explore attrition and reasons for stopping services early based on our clinical expertise of nutrition services in primary care and feedback from the expert research group. Lifestyle change requires sustained behaviour change of daily habits. Multiple visits are usually needed to support adoption of new behaviours. Attrition from a specific program is common in lifestyle service delivery where people decide to stop scheduled participation. Completion of programs is a predictor of successful health behaviour change (Stubbs et al., 2011). Often 50% will drop out of group programs spanning 8-10 weeks in primary care practice. This level of loss to follow-up is well substantiated (Moroshko et al., 2011). Attrition is also a key concept in nutrition interventions in research settings. Delahanty (2010) identifies some provider behaviours or accommodations that have contributed to clinical trials with ~ 90% retention rates, and proposes that these strategies may be useful in clinical settings as well. Suggestions include flexible appointment scheduling, active listening, building self-efficacy, and realistic goal setting. Several of these concepts are included with questions relating to ease of contacting a team member, confidence in maintaining lifestyle changes, and setting relevant goals.

In summary, we have a set of questions that cover concepts that are important to lifestyle services. We do not assume that this is the best set of questions nor that they cover all important
concepts but we believe this tool will assist teams to evaluate the patient experience, identify areas that may benefit from changes, and ultimately improve service quality. In the next section, I discuss the decisions for questionnaire formatting and response options, and suggest strategies for interpretation of the patient responses.

**Questionnaire formatting, response options, and interpretation of responses.**

The formatting of the questionnaire was modelled on the CIHI patient experience questionnaire formatting and informed by Haggerty et al.’s (2011) results from patient focus groups on questionnaire design and formatting. Patient preferences included: having variations in the response scales that fit the question, using large sans serif font, using square boxes instead of circles, and omitting the scoring/coding on the answer scale. We used Arial size 12 font, square boxes, and did not include the score coding. The response options varied to fit the question and included both open-ended and closed-ended options. Closed-ended responses included nominal lists, dichotomous yes/no options, and ordinal responses such as Likert scales.

It is common for patients to respond favourably when evaluating health care services. This skews the distribution of answers and makes it more difficult to discern different levels of positive experience or even if there have been improvement to patient experience if measured over time (Haggerty, 2011). Haggerty (2011) proposes there may be more value in separating response options into a dichotomy of the most positive experience and experiences that could be improved. For example, question 10 presented in Box 1 would be scored as the most positive experience for ‘Always’. All other response options suggest there is room for improvement. For question 14, the ‘Yes, definitely’ response would be scored as the most positive experience, and both ‘Yes, to some extent’ and ‘No’ responses suggest there is room for improvement. Results could be reported as percentages of positive and ‘could be improved’ evaluations and then be
tracked over time. Open-ended responses are often more challenging to analyze. These responses cannot be quantified and it may not be clear what the threshold is for prompting a change (Tsianakas et al., 2012), however, written responses can identify key issues and are more likely to identify negative experiences (de Silva, 2013). These responses could be used by the team to focus their quality improvement efforts or to identify a need to gather more information from patients using different methods.

Box 1: Example questions from May 2014 version questionnaire.

10. How often did the team members explain things to you in a way that you clearly understood?

- □ Always
- □ Usually
- □ Sometimes
- □ Rarely
- □ Never

14. Did you have confidence in the information about nutrition and/or physical activity that the team members gave you?

- □ Yes, definitely
- □ Yes, to some extent
- □ No, not at all

Questionnaire testing

We used cognitive interviewing early in the development process to involve patients as the experts in their own experience of the lifestyle services that they attended. The patient participants in this project reported higher than average health care service usage. Results from the Canadian Survey of Experiences – Primary Health Care (CSE-PHC) 2007-2008 (Statistics Canada, 2010) show that fewer respondents had seen or talked to a family doctor or general
practitioner as often as participants in our project had attended appointments at their family
doctor’s office (Table 9). A direct comparison cannot be made as the questions were slightly
different. The CSE-PHC focused specifically on family doctor contact and ours focused on all
appointments at the family doctor’s office; however it does give a sense that our patient
participants are frequent users of the health care system and in a unique position to give their
experienced input to the questionnaire development.

Table 9: Comparison of number of visits at a family doctor's office within the past 12 months:
Cognitive Interviewing Participants (n=11) vs. Canadian Population.

<table>
<thead>
<tr>
<th>Number of Visits/Contact</th>
<th>Cognitive Interviewing Participants (%)</th>
<th>Canadian Population from CSE-PHC (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>1-2</td>
<td>27</td>
<td>34</td>
</tr>
<tr>
<td>3-5</td>
<td>18</td>
<td>23</td>
</tr>
<tr>
<td>6+</td>
<td>55</td>
<td>14</td>
</tr>
</tbody>
</table>

There are many different styles for conducting cognitive interviews and several different
types of probing strategies. CI is often used as a method to test questionnaires (Beatty & Willis,
2007); however, results may differ depending on the style and strategy people use in conducting
the interviews and how many people analyze results (Conrad & Blair, 2009; Priede & Farrall,
2011; Buers et al., 2013) which brings into question the reliability and validity of the CI process.
Given the flaws noted with the validity and reliability of cognitive interviewing, it might be
tempting to forgo this step, however instead of conceptualizing the process as producing the
perfect questions and questionnaire, it may be used to help describe the problems, be suggestive
of solutions (Carbone, Campbell, & Honess-Morreale, 2002), and support “‘best-informed’
design decisions’ (Conrad & Blair, 2009, p. 304).

As this is the first pass of this new questionnaire, we decided to use a mixture of
strategies in probing in order to come up with as many potential issues as possible – even if it
resulted in false positives (Conrad & Blair, 2009). Primarily, we wanted to know if the questions were understood as intended and whether they were relatively easy to answer. We also wanted to solicit feedback from participants on important concepts to include. In particular, we wanted to identify questions that should be added or removed.

There were some obvious questionnaire wording and formatting problems identified while going through this process. For example, the introductory paragraph was not clear enough to help participants answer the questionnaire with reference to the intended lifestyle services, participants did not follow the skip pattern instructions of the first draft questionnaire, and almost all participants wanted to respond to the question about respect with a response option that was not available (‘always’). There were also problems identified that were unclear as to the best solution. For example, one question was related to comfort with sharing personal information. One participant interpreted ‘personal information’ as non-medical information such as banking details that should be kept private from everyone. There were several participants who found the word ‘appointment’ problematic for interpreting questions. They considered appointments to be one-on-one consultations only and they had attended a group. We debated changing the word to ‘session’ but did not find a word that was completely generic and decided to leave it up to the team using the questionnaire to customize the wording in these questions depending on whether the services were group or individual appointments. It was not possible to correct all the problems, but at least we could try to minimize some of the bigger issues.

As others have noted (Carbone et al., 2002), we found the process of cognitive interviewing improved vague and unclear instructions, changed and expanded response options, and resulted in clearer wording choices. One example of this is using a clearer description of the service being evaluated by including space in the introduction for this purpose. Teams using the
questionnaire are encouraged to include a short description of the program/service being evaluated. During the first round of interviews, several participants commented on not being clear about which exact services they were evaluating. In the second round, there were very few comments related to which service they were considering when answering. Second round interviews were shorter than the first round. Though this may be related to having 8 fewer questions, it also reflected fewer problems with answering questions.

Other aspects of the questionnaire that we wanted to assess were the feasibility of self-administration of this questionnaire and if there was adequate face validity. The published primary care patient surveys and nutrition service questionnaires that we reviewed and included in Appendix A and B range from 8 to 87 questions. We do not know the optimal or threshold numbers of questions acceptable to patients. In fact, respondent burden may be more related to content rather than to length (Rolstad, Adler, & Ryden, 2011); however, we intuited that it would be best to reduce the questionnaire to the priority dimensions/sub-dimensions. Initially we considered one to two pages as a goal length from personal experience of questionnaires used in practice for nutrition services. After testing with patients, our questionnaire has 23 questions over 6 pages. Through the process of interviewing patients, we established the feasibility of the questionnaire length from participants’ comments and found that participants were able to self-administer the questionnaire without many difficulties. Review of the questionnaire by the expert research group and thesis committee assisted to establish face validity.

**Contribution to the bigger quality improvement environment**

Primary care reform in Canada has resulted in the building of teams that aim to address the needs of the population they serve. Family Health Teams in Ontario often include RDs, and occasionally include an exercise specialist or health promoter. The doctor, nurse practitioner,
nurse, or other interdisciplinary health care professionals may also be providing nutrition and physical activity advice or counselling. Specific team-based programs and services are being developed to address lifestyle-related chronic conditions. Nationally and provincially, primary care evaluation is on the agenda with the development of indicators (CIHI) and evaluation frameworks (Ontario primary care performance measurement steering committee, 2013).

We need a way to evaluate not only the clinical outcomes, but the patient experience to improve the care provided. Primary care teams are being asked for patient experience-related quality improvement data; and, as evidenced by the interest from FHTs during recruitment for this project, teams are interested in tools for this area. There are many unpublished and unvalidated patient questionnaires in use to evaluate lifestyle services. If we want to be able to evaluate these services consistently from the patient perspective and be able to compare and spread the programs that have the greatest patient benefit (Gocan, Laplante, & Woodend, 2014), we need to start developing standardized evaluation tools. However, for specific programs to take ownership of their quality improvement data, measures need to be service-specific and detailed enough so that practitioners can act on them (Tsianakas et al., 2012). Lifestyle services are often delivered by multiple providers. Our focus on evaluating team-based care is especially important given the focus on establishing interdisciplinary teams. One of the drawbacks to using this approach is that questions that cover all providers may miss picking up on issues with specific providers or may not identify some negative experiences when overall experience was positive (Haggerty et al., 2011).

Questionnaires may not provide the complete answer to what changes would improve services and how to go about those changes, however, they may act as a screening tool for identifying problems with services (Tsianakas et al., 2012; de Silva, 2013). Throughout this
questionnaire development process we have engaged with providers from multiple primary care teams and hope that this will result in a tool that is generic enough to be applicable in a variety of settings but specific enough to lifestyle services that it will be useful to teams as they evaluate these services from the patient perspective. We are hopeful that our questionnaire will advance the identification of patient experiences to guide quality improvement in lifestyle services.

**Next steps and future research**

The current May 2014 version questionnaire is ready for testing within a lifestyle services program. Next steps could include assessing test-retest reliability and known group validity to explore aspects of reliability and validity. Test-retest reliability will establish if the questionnaire is consistently able to establish similar responses over time. Having patients complete the questionnaire at the time they finish lifestyle services and two weeks later would measure the consistency of answers over a timeframe where it is generally accepted that participants would not remember their responses, and where their experience would not have significantly changed. The questionnaire should be able to differentiate between people who have had positive and negative experiences that could be explored with participant interviews to establish known group validity.

Further testing with patients may also be required to determine whether the questionnaire is able to pick up the issues which are most important to those who have had negative experiences. The current paper version of the questionnaire will need to be adapted to a web-based format to accommodate primary care practice preferences in delivery mode, and this new form will need to be pre-tested for usability. Feasibility testing for practices implementing the questionnaire into their services and an evaluation of the usefulness of the results to quality
improvement initiatives in a variety of team-based lifestyle primary care services would be helpful to further develop the questionnaire and support increased spread of its use.

Further exploration of the Wong and Haggerty patient experience framework conceptualization is warranted given the findings of overlapping dimensions from the provider discussion groups. This research could also expand on the use of a general primary care framework for primary care lifestyle service specific use and involve representation from a variety of health care providers and patients. Patients are rarely involved in the design of patient experience measures (de Silva, 2013). Additional research could expand on the current dimensions/sub-dimensions included and involve patients in further identification of concepts within those dimensions/sub-dimension that they believe would be important to ask about lifestyle services (Jackson, Kinn, & Dalgarno, 2005). Key indicators of good patient experiences in lifestyle services could be developed and benchmarks established for programs to use within their quality improvement initiatives. A full suite of questions could be developed to allow teams to select from the groups of concepts which they believe would be the most useful to them. There is value in having a core set of questions that all services use for lifestyle program comparison purposes, but having flexibility in the additional questions included would allow the information gathered to be tailored and applicable to the team using the questionnaire.
Chapter 7: Conclusion

We have developed a new patient experience questionnaire for the primary care context of team-based nutrition and physical activity services. Building on a Canadian primary health care patient experience evaluation framework and incorporating our experience as health care providers of lifestyle services, we aimed to generate a tool that would be useful to improve services. Both providers and patients were involved in the process and this project demonstrates a method for using the most up to date patient experience framework to develop a context-specific patient experience questionnaire. Providers informed the key aspects to include, which resulted in a focus on accessibility, communication, team functioning, trust, services provided, and patient activation. Patients informed the refining of the questions included and the wording of these questions. The current version consists of 23 questions with a mix of multiple-choice and open-ended answer options. Patient feedback is that this length is feasible. The questionnaire demonstrates basic face validity from content expert review, and is ready to be trialed in lifestyle service programs. Further validity and reliability testing is needed as well as an evaluation of the usefulness of the patient responses to identify areas for service improvements. This is a start to a much-needed patient feedback tool in a growing and ever changing interdisciplinary primary health care environment where one of the main focuses is to improve the patient experience of care.


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### Appendix A: Primary Health Care Self-administered Patient Experience Questionnaires – a selection

<table>
<thead>
<tr>
<th>Questionnaire Title</th>
<th>Main focus</th>
<th>Number of Questions</th>
<th>Question Examples</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAHPS® Clinician &amp; Groups Survey – Visit Survey 2.0 (Agency for healthcare research and quality, 2013)</td>
<td>Patient experience with one specific provider (named in the survey) over the past 12 months and most recent visit, includes 2 questions about the clerks and receptionists</td>
<td>37</td>
<td>In the last 12 months, when you phoned this provider’s office during regular office hours, how often did you get an answer to your medical question that same day? During your most recent visit… …did this provider explain things in a way that was easy to understand? …did this provider seem to know the important information about your medical history? …were clerks and receptionists at this provider’s office as helpful as you thought they should be?</td>
<td>Developed by the U.S. Agency for Healthcare Research and Quality. Consumer Assessment of Healthcare Providers and Systems (CAHPS) has a set of 6 questionnaires for adult, child, 12-month, visit specific available at <a href="http://cahps.ahrq.gov/clinician_group/">http://cahps.ahrq.gov/clinician_group/</a> Covers primary care attributes of accessibility, interpersonal communication, respectfulness (Levesque et al., 2012).</td>
</tr>
<tr>
<td>Comparison of Primary Health Care Models in Ontario: Patient Survey (Dahrouge et al., 2009)</td>
<td>Patient experiences with their primary care provider including access, inter-personal communication</td>
<td>40</td>
<td>When you go to your provider’s office are you taken care of by the same doctor or nurse practitioner each time? Does your provider ask you about your ideas and opinions when planning treatment and care for you or a family member? In today’s visit to your clinic were any of the following subjects discussed with you? (includes subjects of: healthy foods and unhealthy foods; exercise; alcohol consumption)</td>
<td>Used in a study to make comparisons between different models of primary healthcare in Ontario.</td>
</tr>
<tr>
<td>Questionnaire Title</td>
<td>Main focus</td>
<td>Number of Questions</td>
<td>Question Examples</td>
<td>Notes</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Primary Care Assessment Survey (PCAS) (Safran et al., 1998)</td>
<td>Assess patients’ experience of primary care for monitoring and quality improvement planning at physician, group practice, health plan, or delivery system level.</td>
<td>51</td>
<td>When you are sick and call the doctor’s office for an appointment, how quickly do they usually see you? Thinking about talking with your regular doctor, how would you rate the Attention your doctor gives to what you have to say? Which of the following have you ever done because of your doctor’s advice: …tried to drink less alcohol;…changed your diet in anyway; done more exercise…</td>
<td>Covers primary care attributes of accessibility, management continuity, technical quality of clinical care, advocacy, relational continuity, interpersonal communication, respectfulness (Levesque et al., 2012).</td>
</tr>
<tr>
<td>Measuring Patient Experiences in Primary Health Care Survey (CIHI, 2013)</td>
<td>Assess patients’ usual care and specific visit experience.</td>
<td>87</td>
<td>Were there times when persons from your clinic told you different things (that didn’t make sense together) about your health? In the past 12 months, has your clinic provided everything you need to help you manage your health concerns? How confident are you that you can maintain changes in your health habits like diet and exercise, even during times of stress? When you received care for your chronic condition(s), did you get help to make a treatment plan that would work in your daily life?</td>
<td>Pan-Canadian CIHI survey available April 2013 <a href="http://www.cihi.ca/phc">www.cihi.ca/phc</a>.</td>
</tr>
<tr>
<td>Questionnaire Title</td>
<td>Main focus</td>
<td>Number of Questions</td>
<td>Question Examples</td>
<td>Notes</td>
</tr>
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<td>---------------------</td>
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</tr>
<tr>
<td><em>Quality in Family Practice</em> Patient Questionnaire (Levitt &amp; Hilts, 2010)</td>
<td>Assess criteria set out in the <em>Quality in Family Practice</em> Assessment Tool from the patient perspective.</td>
<td>48</td>
<td>Based on your visits to this office, how do you feel about your health care provider’s attitude and behaviour towards you? My provider: (examples) Spends enough time with me; Answers my questions well; Explains when to return for follow-up care. The practice is easy to get into (e.g. wheelchair accessible, parking). There is adequate privacy. The staff behave in a professional manner.</td>
<td>Based on <em>Quality in Family Practice: Book of Tools</em> available at <a href="http://www.qualityinfamilypractice.com">www.qualityinfamilypractice.com</a></td>
</tr>
<tr>
<td><em>General Practice Assessment Questionnaire</em> (GPAQ) (Cambridge Centre for Health Services Research, 2010)</td>
<td>Assess patients’ experience with receptionists, appointments, and service times in general and the physician and nurse communication at the last visit with each.</td>
<td>40</td>
<td>How helpful do you find the receptionists at your GP practice? How important is it to you to be able to book appointments ahead of time in your practice? How good was the last nurse you saw at giving you enough time? How good was the last GP you saw at treating you with care and concern? Thinking about the care you get from your doctors and nurses overall, how well does your practice help you to cope with your health problems?</td>
<td>Originally developed from the PCAS and used in the UK as part of their Quality and Outcomes Framework. Covers primary care attributes of accessibility, technical quality of clinical care, relational continuity, interpersonal communication, respectfulness (Levesque et al., 2012).</td>
</tr>
</tbody>
</table>
Appendix B: Patient surveys related to lifestyle counselling or diet

Patient surveys related to nutrition or lifestyle counselling

<table>
<thead>
<tr>
<th>Authors (Year)</th>
<th>Questionnaire Title</th>
<th>Main focus</th>
<th>Number of Questions</th>
<th>Question Examples</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hauchecorne, Barr, &amp; Sork (1994)</td>
<td>Clients’ Perceptions about Nutrition Counselling (CPNC)</td>
<td>Assess patients’ perception of the effectiveness or value of nutrition counselling. Assess perception of benefits to making dietary changes as well as unintended effects of counselling.</td>
<td>14</td>
<td>The RD provided useful information. After talking with the RD, I know what to eat. After talking with the RD, I felt better emotionally. The RD cared about me. Anyone with my condition should talk with a RD.</td>
<td>Basis for several other surveys including Cook, Nasser, Comfort, and Larsen (2006)</td>
</tr>
<tr>
<td>Vivanti, Ash, &amp; Hulcombe (2007)</td>
<td>Untitled</td>
<td>Assess patient satisfaction with out-patient dietetics consultations in both rural and urban settings</td>
<td>25</td>
<td>I felt understood by the nutrition assistants and dietitians. The nutrition assistants and dietitians came up with a good plan for helping me. The nutrition assistants and dietitians were polite and courteous.</td>
<td>Adapted from Ferguson, Capra, Bauer, and Banks’ (2001) inpatient dietetics patient satisfaction. Both developed and tested in Australia.</td>
</tr>
<tr>
<td>Authors (Year)</td>
<td>Questionnaire Title</td>
<td>Main focus</td>
<td>Number of Questions</td>
<td>Question Examples</td>
<td>Notes</td>
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</tr>
<tr>
<td>Trudeau, E. and Dube, L. (1995)</td>
<td>Diet counselling survey</td>
<td>Assess patient satisfaction with diet counselling of inpatient setting. Components of counselling included: knowledge, facilitation skills, cognitive communication skills, affective communication skills.</td>
<td>12</td>
<td>The dietitian knows my diet well. How are you satisfied with the dietitian's answer to your questions? How are you satisfied with the dietitian's answer to your questions? The dietitian who taught my diet is: (disagreeable, unkind, neither, courteous, very courteous)</td>
<td>Originally developed for in patient setting in French (Quebec).</td>
</tr>
<tr>
<td>Marshall, Floyd, and Forrest (2011)</td>
<td>Consultation Satisfaction Survey</td>
<td>Assess patient experience and satisfaction with the Nurse-led healthy lifestyle clinics</td>
<td>8</td>
<td>The healthy lifestyle advice and education has contributed to my improved health and well-being. I was involved in setting goals that addressed the health issues that matter to me.</td>
<td>No description of survey development. New Zealand program.</td>
</tr>
<tr>
<td>Spikmans et al., (2003)</td>
<td>Untitled</td>
<td>Assess reasons for follow-up non-attendance to a dietitian at a diabetes clinic.</td>
<td>34</td>
<td>Do you think it is useful to visit the dietitian? Do you often have to wait before the dietitian is ready to help you? Is your dietary advice well tailored to your personal dietary habits?</td>
<td>Telephone survey of patients of a diabetes clinic in the Netherlands who had met with a dietitian at least once.</td>
</tr>
<tr>
<td>Authors (Year)</td>
<td>Questionnaire Title</td>
<td>Main focus</td>
<td>Number of Questions</td>
<td>Question Examples</td>
<td>Notes</td>
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<tr>
<td>Otero-Sabogal, et al., (2010)</td>
<td>Untitled</td>
<td>Assess patient satisfaction with the HealthFirst program including lifestyle management support</td>
<td>11</td>
<td>How often did the HealthFirst staff: Treat you with courtesy and respect? Help you make changes in your life like eating healthier, exercising more or taking care your medications?</td>
<td>HealthFirst intervention integrated community health workers into primary care team to support chronic disease management. Telephone survey adapted from California Health Interview Survey and the Consumer Assessment of Healthcare Providers and Systems Survey.</td>
</tr>
</tbody>
</table>
Patient surveys related to the diet specifically

<table>
<thead>
<tr>
<th>Author (Year)</th>
<th>Questionnaire Title</th>
<th>Main focus</th>
<th>Number of Questions</th>
<th>Question Examples</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sato, Suzukamo, Miyashita and Kazuma</td>
<td>Diabetes Diet-Related Quality-of-Life</td>
<td>Assess quantitative and qualitative satisfaction with diet for diabetes and impact on quality of life.</td>
<td>31</td>
<td>Questions related to: Satisfaction with diet, burden of diet therapy, and perceived merits of diet therapy.</td>
<td>Developed in Japan, adapted from the Renal Failure Diet-Related QOL scale.</td>
</tr>
<tr>
<td>Barr and Schumacher (2003)</td>
<td>Nutrition-related QOL Survey 1.4.</td>
<td>Assess health related quality of life in individuals receiving medical nutrition therapy</td>
<td>50</td>
<td>During the last 2 weeks: I took the time to eat the food that was best for me, I beat myself up when I ate the food I felt I shouldn’t have, I rewarded myself with food, My food-related condition has caused problems with sexual relations, My food-related condition has given me trouble walking at a moderate pace for 30 minutes, I felt confident that I would be able to live the rest of my life with these changes in my food.</td>
<td>Includes components of food impact, self-image, psychological factors, social/interpersonal, physical, self-efficacy. Developed in the USA through focus groups, surveys, consensus processes</td>
</tr>
<tr>
<td>Author (Year)</td>
<td>Questionnaire Title</td>
<td>Main focus</td>
<td>Number of Questions</td>
<td>Question Examples</td>
<td>Notes</td>
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<tr>
<td>Ahlgren, Shultz, Massey, Hicks and Wysham (2004)</td>
<td>Diabetes Dietary Satisfaction and Outcomes Measure</td>
<td>Assess the aspects of meal plans associated with satisfaction/ dissatisfaction in DM2 management and patients’ barriers and strategies for following a meal plan</td>
<td>47</td>
<td>Questions related to satisfaction with: a daily controlled diabetes meal plan, diabetes dietary lifestyle, ability to handle a diabetes diet, ability to manage a diabetes meal plan away from home, strategies used to follow a meal plan away from home, making changes in dietary lifestyle, learning about and experimenting with foods</td>
<td>Not specific about the dietitian or person providing/adapting meal plan. USA</td>
</tr>
</tbody>
</table>
RESEARCH ETHICS BOARD – General
REB-G
Certification of Ethical Acceptability of Research
Involving Human Participants

APPROVAL PERIOD: November 4, 2013 to November 4, 2014
REE NUMBER: 13OC028
TYPE OF REVIEW: Delegated Type 1
RESPONSIBLE FACULTY: Brauer, Paula (pbrauer@uoguelph.ca)
DEPARTMENT: Family Relations & Applied Nutrition
SPONSOR(S): N/A

TITLE OF PROJECT: Including patients’ experience to improve lifestyle services in primary care

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human subjects in the above-named research project and considers the procedures, as described by the applicant, to conform to the University’s ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that you adhere to the protocol as last reviewed and approved by the REB. The REB must approve any modifications before they can be implemented. If you wish to modify your research project, please complete the Change Request Form. If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Unexpected events and incidental findings must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Responsible Faculty, the safety of the participants, and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocol.

The Tri-council Policy Statement, 2nd Edition, requires that ongoing research be monitored by, at a minimum, a final report and, if the approval period is longer than one year, annual reports. Continued approval is contingent on timely submission of reports.

Membership of the Research Ethics Board - General: S. Banerjee, Community Member; J. Carson, Community Member; S. Chuang, FRAN (alt); K. Chuang, Graduate Student; J. Clark, PolSci (alt); J. Dwyer, FRAN; M. Dwyer, Legal; S. Ferguson, CME (alt); B. Giguere, Psychology (alt); B. Gottlieb, Psychology; S. Henson, OAG (alt); S. Hickson, COA; L. Kuczynski, Chair; A. Lauzon, OAG, R. Ragan, Legal (alt); C. Rice, FRAN; V. Shalls, SOAN (alt); R. Stansfield, SOAN; J. Wood, Graduate Student (alt); S. Yi, CME.

Approved:
Chair, Research Ethics Board- General

Date: ____________________
Appendix D: Provider discussion group – Facilitator guide

**Group Survey Facilitation Guide - Health Care Providers**

**Preparation:**

**Materials**
- Consent Forms
- Wong & Haggerty Framework outline
- Rate and Rank Surveys
- Pens & paper
- Participant name cards
- Digital Audio-Recorder and extra batteries (AAA)
- Poster Paper & Markers or White-board Markers
- Food & Beverages
- Plates, Utensils, Napkins

**Room Set-up**

Arrange for boardroom seating. Have separate table for food and beverage. Use poster paper or white board for keeping participant ideas and parked questions. The moderator will set up at the front of room with boardroom seating. Note taker to set up out of sight lines separate from the boardroom table.

**Group Discussion Session:**

4. **Welcome participants as they arrive. Provide consent. Let them know about refreshments. Food will be served at the end. Start the discussion group when everyone has arrived and completed the consent form. Turn the digital recorder on. Review the consent form and caution participants regarding the public nature of group participation, and the need for all participants to respect the privacy of others by not discussing who was there or what was said (as described in the consent form) and to speak clearly (don’t interrupt each other) in order to preserve the data. Circulate the framework diagram.**

5. **Review purpose of stakeholder input group surveys:** In order to develop patient experience questionnaires for lifestyle services that are meaningful and useful to patients and providers, these group discussion sessions have been organized to gather your perspectives. We will take a bit of time to review a framework for assessing patients’ experiences of primary care services which we will use as the basis for our patient experience questionnaire for team-based lifestyle services. Then we would like to ask a few specific questions about what dimensions or concepts you would like to see addressed in the questionnaire. In the last 15 minutes I will give you a survey to rate and rank the importance of the primary care dimensions. You will also have a chance to write any additional comments.

6. **Introductions and warm-up question:** Please tell us your name and (a fun fact or comment as determined by moderator).

7. **Primary Care Attributes Framework: Pass out the Wong & Haggerty Dimensions Framework.** Researchers have been laying the groundwork for more quality assessments for some years. This is a
framework developed in Canada. It gives operational definitions to key dimensions of patients’ experiences in primary care. We are planning to use the framework to organize our thinking about evaluating lifestyle programs from the patient perspective.

7.1. Are there any sub-dimensions that particularly seem important to include when thinking about evaluating the patient experience of lifestyle services in primary care?
7.2. Are there specific types of questions within these sub-dimensions that you think would be helpful when you consider making quality improvements to lifestyle services?
7.3. Are there any aspects that are missing from these sub-dimensions, and that you would like to receive patient feedback on?

8. Wrap up and Individual Survey Completion: Thank everyone for their participation. Hand out Demographics and Provider Rate & Rank Survey and framework handout to take home and ask them to complete it prior to leaving. Offer food and beverage. Collect all completed documents.
Appendix E: Provider discussion group – Rate and rank survey

Including patients’ experience to improve lifestyle services in primary care

~Health Care Provider Survey~

ID Number___________

Please rate and rank each of the following primary care attributes that you believe are important to include in a lifestyles services patient experience questionnaire. Keep in mind the aspects of services that are more likely to be possible to change.

<table>
<thead>
<tr>
<th>Patient experience sub-dimensions of primary health care from Wong &amp; Haggerty work</th>
<th>Importance of including in questionnaire. 1= very important 5= not at all important</th>
<th>Ranking of top 5 dimensions to include in questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access-</td>
<td>First-contact Accessibility: Able to get services when needed.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>ibility</td>
<td>Accommodation: Organized in a practical way.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Economic accessibility: Affordable care options.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Communication</td>
<td>General Communication: Concerns are understood and responded to effectively.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Respectfulness: Meet the expectations of how people should be treated.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Shared decision making: Involvement in making decisions about treatment.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Whole-person care: Addressing the physical, emotional and social aspects of a patient’s health.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Continuity and coordination</td>
<td>Relational continuity: I am known and respected over time - ongoing relationships.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Informational continuity: Ongoing knowledge of health care needs.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Coordination: Care and information is coordinated between offices</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Team functioning: working effectively as a team to manage and deliver quality patient care.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Completeness of services</td>
<td>Services provided: Full range of services to meet patients’ health care needs.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Health promotion and primary prevention: Enabling people to improve their health and prevent disorders.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Trust</td>
<td>Trust: allows for risks to be taken based on this expectation.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Patient-reported impacts of care</td>
<td>Patient activation: Ability or readiness to engage in health behaviours.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Patient safety: Reports of errors</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Confidence in the PHC system: Belief that providers deliver safe and technically competent care.</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

Comments:
Appendix F: Provider discussion group – Demographics questionnaire

Demographic Data - Health Care Providers

Date of meeting: ____________________

Please note: You may choose to skip any question that you would prefer not to answer.

Please check the box that best applies to you:

1. Gender identity?
   Male □  Female □

2. How old are you? __________ years old

3. Which of the following describes your specialty?
   Dietitian □
   Pharmacist □
   Mental health counsellor □
   Nurse / Nurse practitioner □
   Physician □
   Administrator □
   Other ____________________ □

4. Do you belong to a Regulatory College? Yes_____ No____

5. If so, please name ________________________________

6. How many years have you been practicing in this specialty? __________years

7. How many years have you been practicing in your current primary care team? __________years
Appendix G: Provider Discussion Group – Recruitment email

**Recruitment email to Executive Directors of FHTs**

Dear [Executive Director name],

We are writing to ask your FHT to participate in a project to develop a patient experience questionnaire for evaluating and improving team-based lifestyle (nutrition and physical activity) services in primary care. As providers you have information about the services you offer in your practice and what kinds of questions would be useful to ask patients. We would appreciate your opinions to help guide the development of the questionnaire.

This project is being conducted by Dr. Paula Brauer, RD, PhD, Associate Professor in Family Relations and Applied Nutrition at the University of Guelph and Anneli Kaethler, MSc candidate and registered dietitian at the Hamilton FHT. This is part of Ms. Kaethler’s Master’s thesis.

If your FHT agrees to participate, we would ask that a minimum of 5 team members (health care professionals and clinic staff) attend a discussion group at your site and complete a survey to help us determine the types of questions to include on the questionnaire. The session will be an hour long at a time and location that is convenient for you. It will be facilitated by a professional moderator, and food will be provided. There is no compensation for participating.

If you are interested in participating or have any questions, please don’t hesitate to contact one of us.

Sincerely,

Paula Brauer, RD, PhD
Associate Professor
Family Relations and Applied Nutrition
University of Guelph
519-824-4120 x54831
pbrauer@uoguelph.ca

Anneli Kaethler, RD, CDE, MSc (candidate)
Family Relations and Applied Nutrition
University of Guelph
519-524-4120 x56174
akaethle@uoguelph.ca

**Recruitment email to FHT RD listserv**

Dear Colleagues, The following email has been sent to your executive directors. We would sincerely appreciate your support in helping us recruit 5-6 different FHTs that are within a 2-3 hour drive from Guelph, Ontario. If you think your team would be interested in participating, please follow up with your executive director and encourage them to get in touch with us.

[Incl: Letter to EDs]
Appendix H: Provider discussion group - Consent form

University of Guelph Letterhead

CONSENT TO PARTICIPATE IN RESEARCH

Including patients’ experience to improve lifestyle services in primary care
~Health Care Provider~

You are asked to participate in a research study conducted by Dr. Paula Brauer, from the Family Relations and Applied Nutrition Department at the University of Guelph and her graduate student, Anneli Kaethler. Anneli is a Registered Dietitian with the Hamilton FHT and this research study will contribute to her Master’s thesis.

If you have any questions or concerns about the research, please feel free to contact:
   Paula Brauer, PhD, RD at: 519-824-4120 ext 54831 or pbrauer@uoguelph.ca
   Anneli Kaethler, RD at: 519-824-4120 ext 56174 or akaethle@uoguelph.ca

PURPOSE OF THE STUDY

The purpose of this study is to identify the aspects of lifestyle services offered in primary care that are most important to include in a new patient experience questionnaire for quality improvement purposes. The information will be used to design a new questionnaire specifically addressing issues in lifestyle change programs and services in team-based primary care (nutrition and physical activity).

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

We will ask you to participate in a 60-90 minute group discussion and survey session with five to nine other health care providers to discuss the key aspects of lifestyle services that you believe should be included in a new questionnaire about patients’ experiences of these services. You will be presented with a list of established primary care attributes to guide the discussion. At the end, you will be asked to rate and rank the aspects you believe would be most important to include in the proposed questionnaire.

The discussion will be led by an external professional moderator. The session will be audio-recorded and a note-taker will be present to further document the discussion. You will also have the opportunity to review the results after all of the discussion groups have completed to provide further comment to the researchers by email. You will not be identified by name in any of the discussion or documented information. Some of the comments you make may be quoted in published reports, but no information will identify the person giving the quotation. A copy of the published report may be requested from Dr. Paula Brauer after the study is completed.

POTENTIAL RISKS AND DISCOMFORTS

There are minimal risks involved in participating in these group survey sessions, but some may feel uncomfortable sharing their views in public. If you do not feel comfortable discussing your views, you will not be singled out for comment. As part of the consent process, all participants will agree to maintain the confidentiality of who took part in these sessions and what was said.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You may benefit from participating in this research as it will support the development of a questionnaire that is intended to be useful and meaningful to healthcare providers for program development. You will have access to this questionnaire once it is developed to use in your setting which will support your quality improvement initiatives.

PAYMENT FOR PARTICIPATION

No payment is being offered for participation.
CONFIDENTIALITY

Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study. Since you will be in a group session, it is important to ensure confidentiality by refraining from any discussion of who took part or what was said once you leave the group.

The researcher will ensure confidentiality of the data collected by taking the following measures: The audio-recordings will be stored on a computer that is password protected. Any printed materials with participant names or identifying information will be locked in a filing cabinet in a secure location. Only the researchers will have access to the information which will be used to develop the questionnaire and may be included as part of the thesis manuscript. Any quotes used will not have a name attached and it will not be identifiable. The audio files will be destroyed after the questionnaire development is complete.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study at the time of withdrawal. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

<table>
<thead>
<tr>
<th>Research Ethics Coordinator</th>
<th>Telephone: (519) 824-4120, ext. 56606</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Guelph</td>
<td>E-mail: <a href="mailto:sauld@uoguelph.ca">sauld@uoguelph.ca</a></td>
</tr>
<tr>
<td>437 University Centre</td>
<td>Fax: (519) 821-5236</td>
</tr>
<tr>
<td>Guelph, ON N1G 2W1</td>
<td></td>
</tr>
</tbody>
</table>

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I have read the information provided for the study “Including patients’ experience to improve lifestyle services in primary care” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

_____________________________________________________________________
Name of Participant (please print)

_____________________________________________________________________
Signature of Participant

_____________________________________________________________________
Date

SIGNATURE OF WITNESS

_____________________________________________________________________
Name of Witness (please print)

_____________________________________________________________________
Signature of Witness

_____________________________________________________________________
Date
Appendix I: Provider discussion group – Member-checking sign-up

Provider sign-up sheets for providing further input after discussion groups.

Including patients’ experience to improve lifestyle services in primary care.

Yes, I would be interested in reviewing the results of the provider group discussion and surveys. Please email me:

Name: ________________________________

Email: ________________________________

Including patients’ experience to improve lifestyle services in primary care.

Yes, I would be interested in reviewing the results of the provider group discussion and surveys. Please email me:

Name: ________________________________

Email: ________________________________

Including patients’ experience to improve lifestyle services in primary care.

Yes, I would be interested in reviewing the results of the provider group discussion and surveys. Please email me:

Name: ________________________________

Email: ________________________________
Appendix J: Questionnaire – First draft

**Nutrition and physical activity lifestyle services experience questionnaire**

We are interested in your experiences using lifestyle services through this clinic. You are being invited to take part in this survey because you have accessed services to change nutrition and/or physical activity habits through your family doctor's office. We are interested in how care is organized at this clinic. Answering these questions will help us to make improvements to the lifestyle services we offer for nutrition and physical activity.

Before you answer, please remember that
- You can choose whether to fill in the survey or not. You can even stop answering at any point.
- Your choice will not affect how well you are treated here.
- No one will know who answered this survey.
- There are no right or wrong answers.

1. **What lifestyle services have you accessed to help you make changes to your nutrition and/or physical activity?**

   - Registered Dietitian
   - Healthy You – Weight Management Group
   - Craving Change
   - Heart Healthy Eating session
   - Living Well with Diabetes
   - Other: ___________________________

2. **How did you find out about these services?**

   - My healthcare provider told me
   - Clinic staff told me
   - I saw a poster in the office
   - A friend told me
   - Other: ___________________________

3. **How did you access these services?**

   - Referred by doctor or nurse practitioner
   - Referred by other health care provider: ___________________________
   - I referred myself
   - Other: ___________________________
4. How long did you wait from the time you were referred to the time you had your first appointment?

□ Less than 2 weeks
□ 2 to 4 weeks
□ 5 to 8 weeks
□ More than 8 weeks
□ I don’t know

5. Did these lifestyle services have a set program? For example a specific number of visits or length of time?

□ Yes
□ No. Skip to question 7.
□ I don’t know. Skip to question 7.

6. Did you stop attending before the program finished?

□ Yes
□ No. Skip to question 9.

If you responded Yes, please share what influenced you to stop attending appointments before the program finished.

__________________________________________________________
__________________________________________________________
__________________________________________________________

7. Did you know what to expect from the lifestyle services program in terms of how many appointments you would have, what you would learn, and the amount of support you would be offered?

□ Yes, definitely
□ Yes, to some extent
□ No, not at all

Comments:

__________________________________________________________
__________________________________________________________
__________________________________________________________
8. Did you stop attending nutrition and/or physical activity appointments before achieving your goals?

☐ No
☐ Yes

If you responded Yes, please share what influenced you to stop attending appointments.

________________________________________________________________________

________________________________________________________________________

9. How often were you able to choose who you met with to help you with changes to your nutrition and/or physical activity?

☐ Always
☐ Usually
☐ Sometimes
☐ Rarely
☐ Never

10. Were you able to talk with a team member about your nutrition and/or physical activity when you wanted to?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, Not at all

Comments:
________________________________________________________________________
________________________________________________________________________
11. How often did you find it difficult to get to lifestyle service appointments or programs because of the additional costs or time it involved? (baby-sitting, parking, transportation, etc)

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Very often

Comments:
____________________________________________________________________________________
____________________________________________________________________________________

Questions 12-24 relate to ALL the different people that you saw to support lifestyle changes at this clinic over the last 12 months:

12. How often did team members explain things to you in a way that you clearly understood?

☐ Always
☐ Usually
☐ Sometimes
☐ Rarely
☐ Never

13. How would you describe the amount of time you had with team members to support your lifestyle changes?

☐ Too short
☐ Just right
☐ Too long
14.  How often did you have to repeat information that should be in your medical record?

□ Never
□ Rarely
□ Sometimes
□ Often
□ All the time

Comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

15.  Were you comfortable sharing personal information with the team?

□ Yes, definitely
□ Yes, to some extent
□ No, Not at all

16.  How often did the team treat you with courtesy and respect?

□ Never
□ Sometimes
□ Often

17.  Did the team consider your personal situation (lifestyle, income, traditions and culture) when making nutrition and/or physical activity recommendations for you?

□ Yes, definitely
□ Yes, to some extent
□ No, Not at all

Comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
18. Were you involved in setting lifestyle goals that address the health issues that matter to you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

Comments:


19. Were you supported in making realistic lifestyle changes that you could carry out in your daily life?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

Comments:


20. Did you and your team work out a lifestyle change plan together?

☐ Yes, often
☐ Yes, sometimes
☐ No

Comments:


21. How often did the people you meet with about nutrition and/or physical activity know what they were talking about?

☐ Always  
☐ Usually  
☐ Sometimes  
☐ Rarely  
☐ Never  

Comments:  
__________________________________________________________________________________  
__________________________________________________________________________________

22. How often were there times when the person you were seeing did not know about lifestyle changes in your plan that another person within your team recommended?

☐ Never  
☐ Rarely  
☐ Sometimes  
☐ Often  
☐ All the time  

23. How often were you told different things (that didn’t make sense together) about your nutrition and/or physical activity?

☐ Often  
☐ Sometimes  
☐ Never  

24. Were there times when you did not try the suggested lifestyle changes because something got in the way?

☐ No  
☐ Yes, sometimes  
☐ Yes, often  

If yes, please share what you experienced:  
__________________________________________________________________________________  
__________________________________________________________________________________  
__________________________________________________________________________________
25. In the last 12 months, has your team provided the information and support you need to make changes to your nutrition and/or physical activity?

☐ Yes, definitely  
☐ Yes, to some extent  
☐ No, not really  
☐ No, not at all  
☐ No, I have not needed information and support

Comments:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

26. How confident are you that you can maintain the changes in your health habits like nutrition and/or physical activity?

☐ Totally confident  
☐ Very confident  
☐ Moderately confident  
☐ A little confident  
☐ Hardly confident at all

27. How has working with the team on nutrition and/or physical activity helped you better manage your health?
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

28. How would you rate the importance of the nutrition and/or physical activity services you received to your overall healthcare? (0 = not important at all, 10 = extremely important) Please circle.

0 1 2 3 4 5 6 7 8 9 10

29. Are there other nutrition and/or physical activity services you would like offered by your team?
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
30. What else would improve the lifestyle services offered through this clinic?

__________________________________________

__________________________________________

__________________________________________

__________________________________________

__________________________________________

__________________________________________

__________________________________________

__________________________________________

__________________________________________

Thank you! Your feedback is important.

It will be used to make improvements to services.
Appendix K: Cognitive interviewing – Interview guide

Cognitive Interviewing Guide

Preparation for the Interview.

1. **Materials** – Ensure to have the following:
   - Consent forms
   - Draft Questionnaires
   - Pens
   - Data collection sheets
   - Digital Audio-recorder with extra batteries (AAA)
   - Grocery store gift cards
   - Bottled waters

2. **Room set up & preparation prior to participant arrival**

   Arrange for a room with privacy and minimal distractions. Arrive before the interview time according the location and agreement with the participant. Interview could be done in a quiet office or other location. Set chairs perpendicular to each other at a table to facilitate conversation. Arrange materials so that they are accessible. Keep gift cards in a secure location. Test audio-recorder. Fill in portion of data collection sheet that can be completed.

If the participant arrives too late to complete the interview:
Inform participant that there is not enough time to complete a thorough interview. Ask if they would like to reschedule the session and if they do, that the interview requires approximately 60 minutes. Thank them for their interest in the project and answer any questions that they have.

If the participant does not attend the interview:
Call the participant and confirm date and time of interview. Let them know you are still interested in them participating. Ask if they would like to reschedule the session and if they do, that the interview requires approximately 60 minutes. Thank them for their interest in the project and answer any questions that they have.
The Interview

Greet the participant. Introduce yourself. Thank the participant for coming and show them where to sit. Offer bottled water.

Establish rapport. Ease anxiety participant may have about the interview by establishing some rapport.

Remind participant about the project. Example script:
The purpose of this project is to make sure the draft patient questionnaire is clear and understandable on its own. The best way to do that is to get feedback from people directly. Based on these interviews we will be revising the questions we are asking.
This project is being conducted by Paula Brauer, associate professor at the University of Guelph, and myself as part of my Master’s Thesis. I am also an employee of the Hamilton FHT but do not work with your family doctor directly.

Obtain informed consent. Review informed consent form. Allow participant to read through and answer any questions that they have.

Key points to highlight:
Thank for agreeing to interview.
Participation is voluntary – participation will not affect care provided, and you may withdraw at any time.
Contribution is confidential – participation is completely separate from the care you receive from the FHT. No information about you or your comments will be shared with any of your health providers.
Describe Audio-recording and note keeping – I will be making notes to help me remember what you are telling me. I will also audio-record this session, so I can make sure I capture your suggestions, in case my notes are unclear. The tape will be used only for this purpose and will be destroyed after revisions are made.
Confirm consent to proceed.

Warm-up think-aloud activity. Example script:
This process we are using to revise the questionnaire is relatively new and so we like to have people practice a few minutes before we start on the actual questionnaire. We use what is called a think aloud approach where we want people to say the first thing that comes to mind as they look over the questions and answers. Your first impressions tell us whether the question and answer options are clear. I am only interested in knowing what is going through your mind. Let’s try a simple exercise to become familiar and comfortable with the ‘think aloud’ process. What questions do you have?

Try to visualize the place where you live, and think about how many windows there are in that place. As you count the windows, tell me what you are seeing and thinking about. (Willis, 1994)

Questionnaire think-aloud introduction. Provide the patient experience questionnaire. Example script:
Just like the exercise where you went through your home counting windows, I would like you to go through this questionnaire and speak whatever is going through your mind. I am interested in what you are thinking as you read and answer these questions.

Probing: planned and spontaneous. To be added to interviewers copy of the questionnaire.
Responses to participants’ questions. Participants may have questions about the questionnaire or the process throughout the interview. Here are some questions and appropriate answers.

<table>
<thead>
<tr>
<th>Question/Situation</th>
<th>Possible Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>“What am I supposed to be doing?”</td>
<td>“I am interested in what you are thinking as you read and answer this questionnaire. Do whatever you need to help you think aloud about the questions.”</td>
</tr>
</tbody>
</table>
| Participant is having difficulty with the think-aloud technique.                | “Tell me what you are thinking.”
                                                                                   | “What thoughts are going through your mind right now?”                                                                                         |
| Participant is doing well with think-aloud technique.                           | “That’s great. Thinking out loud like this is just what I need.”
                                                                                   | “Good. Your comments help me understand what you’re thinking about.”                                                                            |
| Asks you direct questions about why a question is being asked or the purpose of  | “I’m very interested in knowing what questions you have about the project overall. Lets make a note of that question, and review the consent form again. We  |
| the questionnaire.                                                              |  do need to keep on track with the questionnaire review – do you feel you have enough information to proceed? Please continue to express any questions you have while you are answering the questions. It will be helpful to know what questions you have about the questionnaire.” |

Participant demographics questions. Provide participant with the demographics questionnaire and ask them to complete it. They may leave any questions blank that they do not wish to answer.

Interview wrap-up. Example script:
I want to thank you for participating in this study and taking the time to talk with me about this questionnaire. Your involvement will help us develop a questionnaire that will be useful for both patients and healthcare providers to improve the lifestyle services that are offered. Here is a gift card to a local grocery store in appreciation for your participation.

Post-Interview Wrap-up
1. Complete notes on data collection sheet immediately after interview.
2. Transfer audio-recording to computer and document file name on data collection sheet.

CI Guide adapted from:

Appendix L: Cognitive interviewing – Demographics questionnaire

**Demographic Data - Patients**

Date of meeting ____________________

Please note: You many choose to skip any question that you would prefer not to answer.

Please check the box that best applies to you:

1. Gender identity?
   - Male  □  Female  □

2. How old are you?  __________ years old

3. What is the highest grade that you completed in school (circle grade number)

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Grade school</td>
</tr>
<tr>
<td>2</td>
<td>Junior High</td>
</tr>
<tr>
<td>3</td>
<td>High School</td>
</tr>
<tr>
<td>4</td>
<td>College/University</td>
</tr>
<tr>
<td>5</td>
<td>Post graduate</td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
</tr>
<tr>
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<td>15</td>
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<tr>
<td>16</td>
<td></td>
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<tr>
<td>17</td>
<td></td>
</tr>
<tr>
<td>17+</td>
<td></td>
</tr>
</tbody>
</table>

4. How many years have you been a patient with your current family doctor? ____ years

In the past 12 months, how many appointments have you had at your family doctor’s office for yourself or a family member (with any team member)?

- □ None
- □ 1 or 2
- □ 3 to 5
- □ 6 or more

In the past 12 months, have you had appointments with the following health care professionals either for yourself or a family member?

<table>
<thead>
<tr>
<th>Professional</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Family Doctor</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Mental Health Counsellor, Social Worker, Psychologist</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Nurse</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Other:</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Other:</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
In the past 12 months, which health care professionals have worked with you or your family member to change eating habits and/or physical activity?

<table>
<thead>
<tr>
<th>Professional</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Family Doctor</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Mental Health Counsellor, Social Worker, Psychologist</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Nurse</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

In the past 12 months, have you consulted other services outside of your family doctor’s office to change your or your family member’s eating habits and/or physical activity?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical specialist covered by health insurance OHIP</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Bariatric program or gastroplasty clinic covered by OHIP</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Formal commercial diet programs (e.g. Weight Watchers, Jenny Craig, etc.)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Diet books</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Personal Trainer/Gym</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Private Practice Dietitian</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other nutrition counsellor</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Internet sites</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Naturopath, Homeopath, Traditional Chinese medicine or similar</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other:</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
 Appendix M: Cognitive interviewing – Recruitment

We are developing a new questionnaire to ask patients about their experiences. In particular we want to find out more about experiences with services that help people manage their health through nutrition and physical activity.

We have a draft questionnaire and we are looking for people to go through it with us. We want to make sure that it is easy to understand for everybody. We also want to make sure we are asking the right kinds of questions.

If you choose to participate, it will involve 1 hour of your time for a one on one interview with the researcher. As a thank you, we will give you a $25 grocery card.

This research study is being conducted by Dr. Paula Brauer, from the Family Relations and Applied Nutrition Department at the University of Guelph and her graduate student, Anneli Kaethler. Anneli Kaethler is a Registered Dietitian with the Hamilton Family Health Team.

Please contact us or complete the bottom section of this form and return it to your healthcare team.

Anneli Kaethler, RD (519) 824-4120 ext 56174 akaethle@uoguelph.ca

Paula Brauer, PhD, RD (519) 824-4120 ext 54831 pbrauer@uoguelph.ca

Including patients’ experience to improve lifestyle services in primary care.

Yes, I would be interested in participating in this project. Please contact me:

Name: ________________________________

Phone number: ________________________________

Email: ________________________________

I prefer to be reached by: □ phone □ email □ either

If phone is preferred: The best time to reach me is ________________________________

You may leave a message for me: □ yes □ no
Appendix N: Cognitive interviewing – Consent form

University of Guelph Letterhead
CONSENT TO PARTICIPATE IN RESEARCH

Including patients’ experience to improve lifestyle services in primary care
Cognitive Interviewing
~Patient~

You are asked to participate in a research study conducted by Dr. Paula Brauer, from the Family Relations and Applied Nutrition Department at the University of Guelph and her graduate student, Anneli Kaethler. Anneli is a Registered Dietitian with the Hamilton FHT and this research study will contribute to her Master’s thesis.

If you have any questions or concerns about the research, please feel free to contact:

Paula Brauer, PhD, RD at: 519-824-4120 ext 54831 or pbrauer@uoguelph.ca
Anneli Kaethler, RD at: 519-824-4120 ext 56174 or akaethle@uoguelph.ca

PURPOSE OF THE STUDY
The purpose of this project is to make sure that a newly developed patient questionnaire is clear and understandable on its own.

PROCEDURES
If you volunteer to participate in this study, we would ask you to do the following things:

We will ask you to participate in a 60 minute interview that will be audio-recorded. You will be asked to ‘think aloud’ as you complete a questionnaire about your experience with lifestyle services offered in your family doctor’s office. The interviewer will also ask you specific questions about the questionnaire.

POTENTIAL RISKS AND DISCOMFORTS
There are minimal risks involved in participating in a cognitive interview, but some may feel uncomfortable with the think-aloud method.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY
There are no direct benefits to you in participating in this research.

The questionnaire developed through this work may be used by healthcare teams to improve the services they provide.

PAYMENT FOR PARTICIPATION
No payment is being offered for participation. You will receive a $25 gift card to a grocery store as a token of appreciation for participating.

CONFIDENTIALITY
Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study.

The researcher will ensure confidentiality of the data collected by taking the following measures: The audio-recordings will be saved to an encrypted computer and password protected. The audio-recordings will be permanently deleted from the recording device immediately after saving it to the computer. Any printed materials with your name on it will be locked in a filing cabinet in a secure location. Only the researchers will have access to the information which will be used to revise the questionnaire. Your data may be included as part of the thesis manuscript, but will not include names and no one will be able to identify you.
PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study at the time of withdrawal. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Research Ethics Coordinator
University of Guelph
437 University Centre
Guelph, ON   N1G 2W1

Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I have read the information provided for the study “Including patients’ experience to improve lifestyle services in primary care” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

________________________
Name of Participant (please print)

________________________
Signature of Participant
________________________
Date

SIGNATURE OF WITNESS

________________________
Name of Witness (please print)

________________________
Signature of Witness
________________________
Date
Appendix O: Cognitive interviewing – Data collection sheet

~Cognitive Interviewing~

Data collection sheet

<table>
<thead>
<tr>
<th>Date:</th>
<th>Scheduled Time:</th>
<th>Participant ID:</th>
<th>CI Round __</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start time:</td>
<td>End time:</td>
<td>Interviewer:</td>
<td></td>
</tr>
</tbody>
</table>

Documentation completed:
- ☐ Consent Form
- ☐ Demographics

☑ Audio-recording saved to computer

Location:
______________________________

File name:
______________________________

☑ Audio-recording deleted from digital audio-recording

Notes from interview (factors that affected interview, general comments throughout interview)

☐ Gift card given to participant
Appendix P: Cognitive interviewing – Round 1 and 2 Reports

CI issues identified – round 1

**Nutrition and physical activity lifestyle services experience questionnaire**

*Clarify* (word): long title, had to read several times for comprehension

*Suggestions: Change formatting slightly. Patient experience questionnaire: (insert program/service name here)*

We are interested in your experiences using lifestyle services through this clinic. You are being invited to take part in this survey because you have accessed services to change nutrition and/or physical activity habits through your family doctor's office. We are interested in how care is organized at this clinic. Answering these questions will help us to make improvements to the lifestyle services we offer for nutrition and physical activity.

Before you answer, please remember that
- You can choose whether to fill in the survey or not. You can even stop answering at any point.
- Your choice will not affect how well you are treated here.
- No one will know who answered this survey.
- There are no right or wrong answers.

*Intention of instructions: provide context, introduce questionnaire purpose*

**Issues from CI:**
Clarify (word): difficult pronouncing 'accessed'; (word): difficulty pronouncing 'accessed'; (word): difficulty pronouncing 'accessed'

AK Additional comments (instructions): might be useful to have intro/explanation of the services participant is using e.g. Services include..., includes people like...etc.

*Suggestion: change ‘accessed’ to ‘met with’ health care professionals. Add more description of ‘team’ and identify one service/program only that this questionnaire refers to. PB suggestion: slightly modify to simplify and delete ‘your choice will not affect how well you are treated here’.

1. What lifestyle services have you accessed to help you make changes to your nutrition and/or physical activity?

- [ ] Registered Dietitian
- [ ] Healthy You – Weight Management Group
- [ ] Craving Change
- [ ] Heart Healthy Eating session
- [ ] Living Well with Diabetes
Other: _____________________________

**Intention of question:** Context (what services basing feedback on) – would be different for each organization that uses this questionnaire – they would write in the options they offer. Also acts as a ‘marketing’ opportunity as well (might be services listed that pt hasn’t heard of – idea from HCP discussion groups).

**Usefulness to QI:** allows to target services that require improvements based on feedback

**Issues from CI:**
- Clarify (word): 'accessed' was pronounced 'assessed'. ?impact on comprehension of the wording/question; (vague): unsure if all services or just through HFHT or include bariatric clinic accessed through family doctor referral; (ref): no reference to timeframe nor context (i.e. this clinic or elsewhere); (word) - unsure if only services through family doc clinic; (ref): no time reference, talked about services from 3-4yrs ago in another city; (word): difficulty pronouncing 'accessed';
- Knowledge (recall): took >1min thinking about this to come up with answer
- **Response categories** (vague): crav change not clarified as a program so participant treated it as a concept of reducing cravings

**Suggestion:**
Delete this question – and instead allowing organizations to include in the instructions their list of services and then highlight which service THIS questionnaire is asking about. Would help reduce many of the issues identified in CIs related to confusion of answering based on experience of more than 1 service.

2. **How did you find out about these services?**

- My healthcare provider told me
- Clinic staff told me
- I saw a poster in the office
- A friend told me
- Other: _____________________________

**Intention of question:** First-contact (marketing)

**Usefulness to QI:** context as well as identify opportunities for improved marketing

**Issues from CI:**
- Knowledge (K) - RD viewed as 'clinic staff'; (recall): ‘long time ago’ so was difficult to remember
- Assumptions (inapp): assumes only asking about one service but had accessed 2 different services - answered for both
- **Response categories** (missing): website/online, from another group

**Suggestion:**
Keep with changes: Instead of provider ➔ professional (maybe give examples)

3. **How did you access these services?**

- Referred by doctor or nurse practitioner
- Referred by other health care provider: _____________________________
☐ I referred myself
☐ Other: ____________________________

**Intention of question:** First-contact (marketing)

**Usefulness to QI:** identify opportunities for improved self-referral or strategies to access (ie could highlight that HCPs aren’t doing much marketing)

**Issues from CI:**
- Clarify (ref): answered thinking about non-nutr/pa services has accessed
- Assumptions (inapp): assumes only one wait time, but if referred to 2 different services had multiple wait times;
- (inapp): doing more than 2 services and diff answer for each;
- Response categories (over): thought HCP same as doc

**Suggestion:** Keep with change: ‘provider’ to ‘professional’

4. How long did you wait from the time you were referred to the time you had your first appointment?

☐ Less than 2 weeks
☐ 2 to 4 weeks
☐ 5 to 8 weeks
☐ More than 8 weeks
☐ I don’t know

**Intention of question:** First-contact (wait time)

**Usefulness to QI:** could be used to identify wait times longer than organizational targets; but this information could also be identified from administrative data

**Issues from CI:**
- Clarify (word): 'appointment' seen as 1:1, didn't seem to apply to classes/groups, would have wanted words like visit/class/group; (word): unclear which services e.g.all HFHT groups? Only pa/nutr related? Or all services within &outside HFHT?; (ref) uncertain about which 'first appt' as had multiple first sessions/appts with diff services;
- Knowledge (recall): took a few moments to think about all the different programs and how long it took (reported on the months 'aug until dec'); (recall): some difficulty trying to think back >1yr; (recall): couldn't remember, gave rough estimate;
- Assumptions (inapp): assumes same for all services but could be considering multiple services (group, individual); (inapp) - diff answers for diff services.

**Suggestion:** keep with minor wording modifications – e.g. Appointment → ‘session’ or ‘appointment or session’ depending on the service being evaluated
5. Did these lifestyle services have a set program? For example a specific number of visits or length of time?

☐ Yes
☐ No. Skip to question 7.
☐ I don't know. Skip to question 7.

*Intention of question:* Context

*Usefulness to QI:* 

*Issues from CI:* 
**Clarify** (vague): interpreted this as content was structured/set, didn't refer to #sessions etc.
**Assumption** (inapp): assumes same for all services but could be considering multiple services (group, individual);
(inapp) - again different answers for diff services
**Instructions:** Didn't follow skip instructions, could bold it; didn't follow skip instructions;
**Additional comments:** "I didn't get that one"

*Suggestion:* delete

6. Did you stop attending before the program finished?

☐ Yes
☐ No. Skip to question 9.

If you responded Yes, please share what influenced you to stop attending appointments before the program finished.

________________________________________________________________________________________

________________________________________________________________________________________

*Intention of question:* attrition inquiry

*Usefulness to QI:* learn about what influenced non-completers to drop out

*Issues from CI:* 
**Clarify** (ref): wasn't sure how to answer as had started the program x2 (first one cancelled by organizers)
**Instructions:** Skip instructions not highlighted enough, missed the skip; missed skip instructions; didn't follow skip instructions

*Suggestion:* Keep – change to no longer need skip sequence
7. Did you know what to expect from the lifestyle services program in terms of how many appointments you would have, what you would learn, and the amount of support you would be offered?

□ Yes, definitely
□ Yes, to some extent
□ No, not at all

Comments:

Intention of question: General communication (know what to expect) – to be answered by those who 1) didn’t attend ‘set program’ ie answered no to Q5 and those that did attend set program but didn’t complete it ie answered yes to Q6

Usefulness to QI: identifying issues with communication of services offered if not responding ‘yes, definitely’ – the other 2 categories considered ‘needs improvement’. Are we communicating what to expect? Did people drop out b/c they didn’t know what to expect and it wasn’t what they wanted/needed?

Issues from CI:
Assumption: (db): multiple concepts, said 'no' even though some info was yes, some no. (db): went through each component and answered yes to each;
Response categories (oe): commented on not adding anything to comments as if thought perhaps pressure to add something;

Suggestion: keep - change wording of ‘lifestyle services program’ if change other wording in the questionnaire – to keep consistent

8. Did you stop attending nutrition and/or physical activity appointments before achieving your goals?

□ No
□ Yes

If you responded Yes, please share what influenced you to stop attending appointments.

Intention of question: attrition – answered by those who stopped attending a ‘set program’ and those who didn’t go to set program.

Usefulness to QI: identify reasons for stopping attending (hopefully identify what might help reduce attrition)
**Issues from CI:**

- **Clarify (word):** 'achieving' is interpreted as complete/done, no more changes to be made, but it's not that easy. Nutr/PA difficult to fully achieve.; (word): 'appointment' vs 'course' - would have different answers for both; (Ref): unclear reference period (this set of RD referrals or previous referrals as well?); (ref): thought about outside services/programs;

**Suggestion:** delete – do not need if change previous question skip sequence.

9. **How often were you able to choose who you met with to help you with changes to your nutrition and/or physical activity?**

- □ Always
- □ Usually
- □ Sometimes
- □ Rarely
- □ Never

**Intention of question:** first-contact (provider of choice was concept that came from HCP discussion groups). Intention was for pts to think about whether they were able to see their doc/NP/RD/kin etc (which HCP they saw) or even if then had a choice of which RD (for example) they could meet with

**Usefulness to QI:** not sure if there would be one if there are not multiple providers available to access these services from

**Issues from CI:**

- **Clarify (word):** awkward reading it, read 3-4 times, not clear, 'you mean choose the person?'; (word): awkward = read multiples times and confused about meaning; (word) - read several times, emphasizing 'how often', and 'choose', 'met'; (vague): initially responded 'sometimes' but then in describing process said "in a sense there is no choice. The staff are there";

**Assumptions (Inapp):** choice is not available in most situations; (inapp): not usual to get a choice

**Comments:** Identified by 001 & 003 as Q could delete, not likely to improve services

**Suggestion:** Delete question.

10. **Were you able to talk with a team member about your nutrition and/or physical activity when you wanted to?**

- □ Yes, definitely
- □ Yes, to some extent
- □ No, Not at all

**Comments:**
**Intention of question:** first-contact – timely access

**Usefulness to QI:** identify issues of access to information/support (yes, to some extent and no indicate needs improvement) – might initiate exploration of alternate methods of communication/access (e.g. Phone/internet/drop-in times) or increase advertising of methods of accessing info/support

**Issues from CI:**

- **Clarify** (word): team member didn't cover all the people that may have been involved (e.g. Thought RD, but didn't think MD); (word): "what do you mean by 'a team member'?"; "when you wanted to" literally or realistically?; (vague): "when you wanted to" might not be realistic;
- **Assumptions** (inapp): pts don't necessarily view the various people they have appts with as their 'team' -considered only FD as 'team', not RD saw once "not seeing them regularly", nor group facilitators. ; (inapp): thought only of RD facilitators of group, not other RD in office or MD ie not having same concept of 'team' as is intended;
- **Response categories** (miss): thought something was missing between definitely and to some extent

**Suggestion:** Keep – consider clarifying ‘team’ in instructions at beginning of questionnaire; change to ‘contact’ instead of ‘talk’ as there may be other ways to connect with HCPs e.g.email

11. How often did you find it difficult to get to lifestyle service appointments or programs because of the additional costs or time it involved? (baby-sitting, parking, transportation, etc)

□ Never
□ Rarely
□ Sometimes
□ Often
□ Very often

Comments:

__________________________
__________________________

**Intention of question:** economic accessibility – identify barriers to attending appts (not just ‘$ cost’ but others as well)

**Usefulness to QI:** identifies opportunities for making services more accessible or convenient either financially or time-related. May not get at exactly what changes unless comments are added, however might identify if there is huge issue and might want to explore further with patients.

**Issues from CI:**

- **Clarify** (word): examples are all cost related - could add time related eg: work schedule, family priorities, etc.;
- **Assumptions** (db): uncertain if ok together or separate
- **Comments:** "very relevant"
**Suggestion:** Keep with changes – add time related examples such as work schedule, other commitments; try simplifying wording of question slightly

Questions 12-24 relate to ALL the different people that you saw to support lifestyle changes at this clinic over the last 12 months:

12. How often did team members explain things to you in a way that you clearly understood?

- □ Always
- □ Usually
- □ Sometimes
- □ Rarely
- □ Never

**Intention of question:** General Communication

**Usefulness to QI:** identify issues with clarify of communication

**Issues from CI:**

- **Knowledge** (recall): hard to think of specific situations where didn't. said "always, I guess... Yeah they explained it."
- **Assumptions** (inapp): team member interpreted to include other participants of a group program, not exclusively the HCPs - can't assume all interpret 'team' the same;

**Suggestion:** Keep

13. How would you describe the amount of time you had with team members to support your lifestyle changes?

- □ Too short
- □ Just right
- □ Too long

**Intention of question:** General Communication (adequate time together – was concept from HCP discussion groups)

**Usefulness to QI:** identify issues of service length

**Issues from CI:**

- **Clarify** (word): wasn't clear if it was the sessions length or the overall services amount of time
- **Response categories** (mism): not quite right for thinking about programs and individual appointments (different concepts)

**Suggestion:** Keep, change to try to get at total/overall time with the service.
14. **How often did you have to repeat information that should be in your medical record?**

- □ Never
- □ Rarely
- □ Sometimes
- □ Often
- □ All the time

Comments:

Intention of question: Information continuity (providers have access to information they need – from HCP discussion groups)

Usefulness to QI: highlight issues with either lack of information sharing between team members or with providers not reviewing chart thoroughly; but may not be applicable to group sessions or may be providers’ standard practice to review/ask about medical information themselves

Issues from CI:
Assumptions (inapp): confusing given only in a group and never expected to have access to medical record;
Response categories (miss): was never asked anything so would say ‘does not apply’;
Comments: thought this questions n/a for a group program (no access to chart)

Suggestion: Delete.

15. **Were you comfortable sharing personal information with the team?**

- □ Yes, definitely
- □ Yes, to some extent
- □ No, Not at all

Intention of question: Trust (in provider)

Usefulness to QI: identifying lack of trust issues? Very challenging aspect to repair if lack of trust is identified.

Issues from CI:
Clarify (vague): wondered what is meant by 'personal info' (medical info, feelings?)

Suggestion: Keep, change wording to be consistent – team members.
16. How often did the team treat you with courtesy and respect?

☐ Never
☐ Sometimes
☐ Often

*Intention of question:* Respect (feel respected)

*Usefulness to QI:* Never/sometimes indicates issues that likely to need more exploration

*Issues from CI:*
- **Response categories** (miss): wanted 'always' as an option; (miss): first thought of answering 'always' so would want this as an option; (miss): said "it was always often"; (miss): responded "always" without reading the response options; (miss): "they often did, well they always did";

*Suggestion:* Keep, change wording to be consistent – team members. Keep answer options as is – these are directly from CIHI questionnaire.

17. Did the team consider your personal situation (lifestyle, income, traditions and culture) when making nutrition and/or physical activity recommendations for you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, Not at all

*Comments:

___________________________________________________________________________
___________________________________________________________________________

*Intention of question:* Whole-person care

*Usefulness to QI:* Can identify issues but not specific unless comments added – if yes, to some extent or no predominant indicates HCPs need to be more in tune with personal situation

*Issues from CI:*
- **Clarify** (vague): 'not sure what this means':
- **Knowledge** (recall): thought about doc and med prescriptions
- **Assumptions** (inapp): not making specific recommendations for individual in a group setting;
- **Response categories** (miss): thought something was missing between definitely and to some extent

*Suggestion:* keep with changes for wording consistency

18. Were you involved in setting lifestyle goals that address the health issues that matter to you?
19. Were you supported in making realistic lifestyle changes that you could carry out in your daily life?

- Yes, definitely
- Yes, to some extent
- No, not at all

Comments:

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**Intention of question:** Shared decision making (goals that matter to pt)

**Usefulness to QI:** identifies issues with collaboration between pt/provider and need for providers to change strategies for goal setting

**Issues from CI:**
- Clarify (word): unsure what 'supported' means in this context
- Knowledge (recall): difficulty recalling back to different situations
- Comment: same concept as 18 and could be deleted (003)

**Suggestion:** Delete
20. Did you and your team work out a lifestyle change plan together?

☐ Yes, often
☐ Yes, sometimes
☐ No

Comments:

Intention of question: Shared decision making (joint discussion)

Usefulness to QI: identifies issues with collaboration between pt/provider

Issues from CI:
Clarify (word): 'lifestyle change plan' again caused issues - perception of what this is
Assumptions (inapp): didn't have 1:1 time really did the plan on own, question doesn't quite apply; (inapp): assumes 1:1 sessions; (inapp): would be different based on the different program experiences;
Instructions: previous instructions to think about past 12 months not remembered by this point and thought about program from 3-4yrs ago
Comments: same concept as 18 and could be deleted (003)

Suggestion: delete – would not apply to group sessions, ok for 1:1 but duplicate

21. How often did the people you meet with about nutrition and/or physical activity know what they were talking about?

☐ Always
☐ Usually
☐ Sometimes
☐ Rarely
☐ Never

Comments:

Intention of question: Trust – information from providers

Usefulness to QI: tricky – trust issues difficult to change – however there is value in knowing about an issue that may affect experience

Issues from CI:
Clarify (word): 'how often' was awkward
Knowledge (know): "technically they all went to school for what they did and they should all know what they are talking about" - might not know if they really know.
Sensitivity (content): got the sense didn't want to be critical "they have to know what they're doing or else they wouldn't be doing it"

**Suggestion:** Change the question - related to ‘trust the information’ and maybe also test question of ‘trust the HCP’ – use confidence instead of ‘trust’ – based on CIHI question.

### 22. How often were there times when the person you were seeing did not know about lifestyle changes in your plan that another person within your team recommended?

- □ Never
- □ Rarely
- □ Sometimes
- □ Often
- □ All the time

*Intention of question:* Info Continuity (communication within chart or between providers within one team)

*Usefulness to QI:* identify issues related to info continuity and ?team function

*Issues from CI:*
Clarify (word): confusing question wording, read several times before answering.; (word): long, read several times; (word): confusing sentences -too long ?sentence structure; (word) - thought about other participants suggestions as considered these people part of the team;
Knowledge (know): unsure of what team does behind the scenes (not within the person's knowledge)
Assumptions (inapp): wouldn't expect everyone to know the others plans (e.g. Bariatric to FD); (inapp): would respond n/a as didn't think had multiple people involved.;

*Suggestion:* delete – don’t know that this question really pertinent – info cont within top 10 but not top 5 of HCP discussion groups.

### 23. How often were you told different things (that didn't make sense together) about your nutrition and/or physical activity?

- □ Often
- □ Sometimes
- □ Never

*Intention of question:* team function (consistent messaging – concept highlighted in HCP discussion groups)

*Usefulness to QI:* identifies areas for improvement in consistency of messaging between different HCPs

*Issues from CI:*
Clarify (word): 'together' didn't make sense. Read several times and suggested taking 'together' out; (word) when reading out loud skipped saying 'together'; (vague): seemed to understand this as info not making sense to oneself, not that was receiving conflicting info from different people; Knowledge (recall): hard time thinking of a situation "nothing stands out";

Suggestion: keep with changes – remove 'your'

24. Were there times when you did not try the suggested lifestyle changes because something got in the way?

☐ No
☐ Yes, sometimes
☐ Yes, often

If yes, please share what you experienced:

________________________________________________________________________________________

________________________________________________________________________________________

Intention of question: EconAccessibility /Pt activation

Usefulness to QI: may identify barriers that HCPs may help reducing but may not be changeable either

Issues from CI:
Sensitivity (cont): might be hard for some people to be honest
AKcomment: does not fit within the 12-24 instructions of ‘about all the different people’

Suggestion: keep – separate from the 12-24 grouping

25. In the last 12 months, has your team provided the information and support you need to make changes to your nutrition and/or physical activity?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not really
☐ No, not at all
☐ No, I have not needed information and support

Comments:

________________________________________________________________________________________

________________________________________________________________________________________

Intention of question: Services provided – meeting needs
Usefulness to QI: identifies if there are gaps to services that might benefit pts

Issues from CI:
Clarify (word): 'team' not one cohesive team providing services makes it difficult to answer
Instructions: Need to clearly define 'team' and possibly have pt write down the services they've accessed in past yr to reference/clarify what this questionnaire is asking about. Not clear enough that this questionnaire is asking about particular services.

Suggestion: Keep with changes – change ‘team’ to be consistent, remove specific time frame as we change to specified services questionnaire

26. How confident are you that you can maintain the changes in your health habits like nutrition and/or physical activity?

☐ Totally confident
☐ Very confident
☐ Moderately confident
☐ A little confident
☐ Hardly confident at all

Intention of question: Pt activation – action on goals
Usefulness to QI: identifies if there is need for more confidence building techniques

Issues from CI: no comments

Suggestion: keep – simplify wording –remove ‘health habits’

27. How has working with the team on nutrition and/or physical activity helped you better manage your health?

Intention of question: Pt activation – action on goals
Usefulness to QI: get sense of what is working well

Issues from CI:
Clarify (word): sometimes unsure who to consider as 'team'. Difficult to answer if feel positive about some interactions, negative about others;
Assumptions (inapp): assumes that the team actually did help person better manage health
Response categories (oe) "I don't know how to answer that one" though did eventually talk through and wrote down something;
Comment: "liked this Q"
28. How would you rate the importance of the nutrition and/or physical activity services you received to your overall healthcare? (0 = not important at all, 10 = extremely important) Please circle.

0 1 2 3 4 5 6 7 8 9 10

Intention of question: Context (importance of the services to the pt)

Usefulness to QI: ?context

Issues from CI:
Clarify (tech): 'healthcare' not really interpreted as the service but more thought of it as 'health'; (word): 'services... received' vs nutr/PA themselves; (word): seemed to interpret initially as nutr/PA importance rather than services importance.; (word): unclear if just to group or 1:1 sessions or both as would be different answer for different services; (vague/word): "I've enjoyed everything so far, so I'd say a 9" - didn't quite grasp concept;
Assumptions (inapp): assumes past tense 'received' as if services are over but in actuality person hadn't completed yet
Formatting (Q order): might be better to have this question earlier in the Q order 'near the beginning'

Suggestion: put closer to beginning of questionnaire (after identifying which service they are referring to in the questionnaire), change wording to test if it is better understood 'how would you rate the importance of this service to your overall healthcare?'

29. Are there other nutrition and/or physical activity services you would like offered by your team?

Intention of question: Services provided – suggest improvements (additional services)

Usefulness to QI: offers pts input on new services that could be offered

Issues from CI:
Clarify (word) difficult reading - makes AK wonder if missing a 'that' before you?
Knowledge (recall): "not that I can think of at this second"
Response categories (mism): in this open ended space participant mentioned other aspects of the current services content, not other services themselves

Suggestion: Integrate this concept with next question.

30. What else would improve the lifestyle services offered through this clinic?
Intention of question: Services provided – suggest improvements (to anything in general about the services, current or additional)

Usefulness to QI: offers pts input on any improvements that could be made not already asked about

Issues from CI:
Clarify (word): 'lifestyle services' not how participant thought of these services nor how they are advertised/referred to in the clinic - added to confusion of answering several of the questions; (word): too similar of wording to previous question on first reading, reread and then understood the nuanced difference; (word): thought of this as same question as previous; seems too similar to previous question;
Response categories (oe): feels pressure to fill in all the lines if there are many lines
Sensitivity (cont): would want a space to provide feedback on negative experiences;

Suggestion: Integrate with previous question.

Thank you! Your feedback is important.

It will be used to make improvements to services.
CI issues – Round 2 Report

Patient experience questionnaire:

*(insert program/services name here)*

We are interested in your experiences using lifestyle services through this clinic. You are being invited to take part in this survey because you have met with one or more team members through your family doctor’s office to change your nutrition and/or physical activity habits.

Team members may include the dietitian, exercise specialist, doctor, nurse, or other people working in the clinic. Consider all the people working with you to support changes to your nutrition and/or physical activity. Answering these questions will help us to improve these services.

Before you answer, please remember that:

- You can choose whether to fill in the survey or not.
- You can skip any question you are not comfortable answering.
- No one will know who answered this survey.
- There are no right or wrong answers.

Insert information about the service/program being evaluated. (max 80-100 words)

All questions are about: *(insert program/service name)*

Intention of instructions: provide context, introduce questionnaire purpose

Issues from CI:
**Instructions:** confusing b/c 'all people' may not be part of the specific program being asked about

**AK thoughts:** May need to alter this further - more individualized based on organization using it. Conflicting instructions ('consider all the people…' vs just the one program)

**Suggestion:** reword introduction and make further modifiable by program using it, have program description right at top

1. How did you find out about this service?

- □ A healthcare professional told me
- □ A clinic staff told me
- □ I saw a poster in the office
□ A friend told me
□ Other: _____________________________

*Intention of question:* First-contact (marketing)

*Usefulness to QI:* context as well as identify opportunities for improved marketing

*Issues from CI:*  
Response categories: (overlap) - clinic staff could also be a HCP "not sure if NP considered HCP or staff";

*Additional comments:* consider changing to make consistent with next question – asking about specific providers, include nurse as many clinics across Canada may not have NP  
*Suggestion:* Keep – with modifications to answer options

2. **How did you access this service?**

□ Referred by doctor or nurse practitioner  
□ Referred by other healthcare professional: _____________________________  
□ I referred myself  
□ Other: _____________________________

*Intention of question:* First-contact (marketing)

*Usefulness to QI:* identify opportunities for improved self-referral or strategies to access (ie could highlight that HCPs aren’t doing much marketing)

*Issues from CI:*  

*Additional comments:* as with #1 above  
*Suggestion:* Keep with modifications to answer options

3. **How would you rate the importance of this service to your overall healthcare?** Please circle. (0 = not important at all, 10 = extremely important)

0 1 2 3 4 5 6 7 8 9 10

*Intention of question:* Context (importance of the services being available within their healthcare services)

*Usefulness to QI:* context

*Issues from CI:*  
Clarify: (word)- read as 'health' not 'healthcare' and understood as health when probed. Thought 'as part of your healthcare' would be clearer; (word) - 'healthcare' interpreted as 'health'; (word) - 'what do you mean by service' - didn't see group program as a 'service' would prefer term 'program'; (tech): healthcare interpreted as 'health'. actually read the sentence using health, not healthcare; (tech) thought of 'healthcare' as 'health' and that question was asking about importance of the service to their health.  
*Formatting:* thought this was summary type questions, suggested be put near the end;
Additional comments: from discussion may be more useful to look at it from how pts are interpreting – importance of the service to their health.

Suggestion: change wording and intention to importance to their health

4. How long did you wait from the time you were referred to the time you had your first appointment?

- Less than 2 weeks
- 2 to 4 weeks
- 5 to 8 weeks
- More than 8 weeks
- I don’t know

Intention of question: First-contact (wait time)

Usefulness to QI: could be used to identify wait times longer than organizational targets; but this information could also be identified from administrative data

Issues from CI:
clarify: (vague) interpreted 'appointment' as first contact ie by phone to set up going to group; (word) - 'appointment' was confusing. 'Don't think of group program as an appointment' (could rephrase it: "How long was the waiting period before you could get into the program?"); (word) "this is for this program? you're calling it a first appointment." - thought of appointment as 1:1, suggested using 'program' if thinking about HY.
Knowledge: (recall) - "I know there was a waiting period. To be honest I’m guessing at it. I don't think I waited 2 full months";

Suggestion: depending on the program using this questionnaire suggest modify wording. Ie if program is individual appointments using ‘appointment’, if group program using ‘group session’. Keep.

5. Did you stop attending before the program finished?

- No
- Yes

If you responded Yes, please share what influenced you to stop attending appointments before the program finished.

Intention of question: attrition inquiry

Usefulness to QI: learn about what influenced non-completers to drop out

Issues from CI: none identified
**Suggestion:** Keep. Modify to make consistent ‘if’ statement with others in questionnaire.

6. **Did you know what to expect from the nutrition and/or physical activity services in terms of how many appointments you would have, what you would learn, and the amount of support you would be offered?**

- Yes, definitely
- Yes, to some extent
- No, not at all

Comments:

________________________________________________________________________

________________________________________________________________________

**Intention of question:** General communication (know what to expect) – to be answered by those who 1) didn’t attend ‘set program’ ie answered no to Q5 and those that did attend set program but didn’t complete it ie answered yes to Q6

**Usefulness to QI:** identifying issues with communication of services offered if not responding ‘yes, definitely’ – the other 2 categories considered ‘needs improvement’. Are we communicating what to expect?

**Issues from CI:**
- **Clarify:** (word) "that 'appointment' throws me" - thought about 1:1 appointments, not group sessions.
- **Assumptions:** (db) may have known how many appts but not level of support;
- **Additional comments:** "important question";

**Suggestion:** Keep. same as with Q4. Vary wording depending on group vs individual appointment.

7. **Were you able to contact a team member about your nutrition and/or physical activity when you wanted to?**

- Yes, definitely
- Yes, to some extent
- No, not at all

Comments:

________________________________________________________________________

________________________________________________________________________

**Intention of question:** first-contact/access – timely access
Usefulness to QI: identify issues of access to information/support (yes, to some extent and no indicate needs improvement) – might initiate exploration of alternate methods of communication/access (e.g. Phone/internet/drop-in times) or increase advertising of methods of accessing info/support

Issues from CI:
Knowledge: (recall) - "not sure. Know about an email and a cell phone, but not sure how to answer that one"
Response category: (miss) none of the options fit her response as she never felt she needed to contact; (miss) no answer option fit if didn't have to 'but I'm sure I could if I wanted to';
Additional comments: didn't read full Question - not past 'team member' and responded giving examples of person they heard from /phone number they had from signing up for the group;
AK thoughts: maybe add box for 'I didn't need to contact a team member'; could change to 'if you wanted to' - but this changes the meaning of the question;

Additional comments: would work within ‘all the different people’ section below
Suggestion: consider adding answer option of ‘I did not feel the need to contact a team member’

8. How often was it difficult to get to nutrition and/or physical activity appointments because of the additional costs or time it involved (e.g. childcare, parking, transportation, work schedule, other commitments)?

□ Never
□ Rarely
□ Sometimes
□ Often
□ Very often

Comments:

Intention of question: economic accessibility – identify barriers to attending appts (not just ‘$ cost’ but others as well)

Usefulness to QI: identifies opportunities for making services more accessible or convenient either financially or time-related. May not get at exactly what changes unless comments are added, however might identify if there is huge issue and might want to explore further with patients.

Issues from CI:
Clarify: (word) 'how often was it difficult...' didn't flow right for participant. Suggested 'Was is difficult...? How often?'; (word) "i dont' know what that means...I don't see a nutritionist". appt thought of as 1:1, group might be considered 'session'; (word) 'how often was it difficult' seemed awkward wording when reading; (word) 'how often was it difficult' re-read a couple times, slowing down - seemed awkward. 'appointments' also thought of 1:1.

Suggestion: Vary wording based on context. Return to original CIHI wording of ‘were there times when you found it difficult…’
Questions 9-16 relate to ALL the different people (team members) that you saw to support nutrition and/or physical activity changes at this clinic:

**Issues from CI:**

**Instructions:** 'at this clinic' confuses b/c services might not be at family doc clinic
One participant stopped reading out loud at 'support' and seemed to jump over 'nutr & PA' went right to next question.

**Additional comments:** some answers have comment space, others do not. Consider making space for comments on all, or add comment to space beside questions.

**Suggestion:** Make more context specific. Be consistent with comment space.

9. **How often did the team members explain things to you in a way that you clearly understood?**

- □ Always
- □ Usually
- □ Sometimes
- □ Rarely
- □ Never

**Intention of question:** General Communication

**Usefulness to QI:** identify issues with clarify of communication

**Issues from CI:**

**Clarify:** (word)- unsure of 'team members' - might consider HY facilitators only, or doc office with RD, or HFHT (ie 'all of it');

**Additional comments:** issue above was only 1 individual, would be resolved with clearer instructions.

**Suggestion:** Keep as is.

10. **How would you describe the total amount of time you had with the team members to support your lifestyle changes?**

- □ Too short
- □ Just right
- □ Too long

**Intention of question:** General Communication (adequate time together – was concept from HCP discussion groups)

**Usefulness to QI:** identify issues of service length – would need to explore further to determine session length or program length

**Issues from CI:**
Clarify: (vague) thought length of time referred to each session, not total length of program; (vague) "it just depends on what I wanted to talk about" - referring to when met 1:1 with RD (questionnaire was trying to focus on HY group).

Response categories: (oe) - wanted to be able to add comments and explain answer here;

Suggestion: Change wording to be about the program length, move to outside of the ‘all the different people’ section

11. Were you comfortable sharing personal information with the team members?
   □ Yes, definitely
   □ Yes, to some extent
   □ No, not at all

Intention of question: Trust (in provider)

Usefulness to QI: identifying lack of trust issues? Very challenging aspect to repair if lack of trust is identified.

Issues from CI:
Clarify: (word) - thought of 'personal' info as things like banking, that that should be kept private, no lifestyle;
Assumptions: (inapp) - 'we didn't really have to share personal information. If they asked me anything, I'd be comfortable" - assumes personal info asked about;

Suggestion: keep

12. How often did the team members treat you with courtesy and respect?
   □ Never
   □ Sometimes
   □ Often

Intention of question: Respect (feel respected)

Usefulness to QI: Never/sometimes indicates issues that likely to need more exploration

Issues from CI:
Response categories: (miss) - said "always" before reading the responses then commented "there should be always here. Often doesn't cut it"; (miss) - "all the time" response before reading answer options; (miss) "always, they're always..."; (miss) said 'all the time' first before answering;

Suggestion: keep – change answer options to 5 point scale (almost all participants added/wanted ‘always’)

13. Did the team members consider your personal situation (lifestyle, income, traditions, and culture) when making nutrition and/or physical activity recommendations for you?
   □ Yes, definitely
14. Did you have confidence in the information about nutrition and/or physical activity that your team members gave you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

_Intention of question:_ Trust – information from providers

_Usefulness to QI:_ tricky – trust issues difficult to change – is there value in knowing about an issue that may affect experience anyway?

_Issues from CI:_

**Sensitivity:** (general) - "oh absolutely! They are dietitians, I believe them."; "because it's her profession and she has the training for it"

**AK comments:** ?hesitant to critize/question; ‘your team member’ is inconsistent with rest of questions ‘the team members’

_Suggestion:_ change ‘your’ to ‘the’ for consistency

15. Did you have confidence in the team members who spoke with you about nutrition and/or physical activity?

☐ Yes, definitely
□ Yes, to some extent
□ No, not at all

**Intention of question:** Trust - the providers

**Usefulness to QI:** tricky – trust issues difficult to change – is there value in knowing about an issue that may affect experience anyway?

**Issues from CI:**
**Additional comments:** found was very similar to last question

**Suggestion:** delete (trust in provider #11 also covers this)

16. **How often were you told different things (that didn’t make sense together) about nutrition and/or physical activity?**

□ Often
□ Sometimes
□ Never

**Intention of question:** team function (consistent messaging – concept highlighted in HCP discussion groups)

**Usefulness to QI:**

**Issues from CI:**
**Clarify:** (vague) read multiple times. At one point interpreted as 'told multiple things/options/alternatives' as a positive experience, bracket may not be read "yeah that threw me off".

**Suggestion:** keep

17. **Have your team members provided the information and support you need to make changes to your nutrition and/or physical activity?**

□ Yes, definitely
□ Yes, to some extent
□ No, not really
□ No, not at all
□ No, I have not needed information and support

**Intention of question:** Services provided – meeting needs

**Usefulness to QI:** identifies if there are gaps to services that might benefit pts

**Issues from CI:**
Assumptions: (db) - thought it might be different answer for nutrition and PA; (db) - agreed with info provided, 'don’t know about support' - might separate questions;
AK thoughts: 'your team member’ is inconsistent with rest of questions 'the team members'

**Suggestion:** keep with change ‘your’ to ‘the’ for consistency

18. Were you involved in setting nutrition and/or physical activity goals that address the health issues that matter to you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

**Intention of question:** Shared decision making (goals that matter to pt)

**Usefulness to QI:** identify issues with collaboration between pt/provider if responding yes, to some extent or no

**Issues from CI:**
Clarify: (vague) involved - taken as interacting with team members. After reading several times did understand and interpret as intended;
Additional comments: read this as how involved this person was in discussion during groups (didn't read whole question through before answering)

**Suggestion:** keep

19. How confident are you that you can maintain the changes in your nutrition and/or physical activity?

☐ Totally confident
☐ Very confident
☐ Moderately confident
☐ A little confident
☐ Hardly confident at all

**Intention of question:** Pt activation – action on goals

**Usefulness to QI:** identifies if there is need for more confidence building techniques?

**Issues from CI:**
Assumptions: (db): had different answer for nutrition and for PA.
Response category: (open) - added comment despite no comment space. ?add comment space

**Additional comments:** may be important to separate nutrition and pa for this one

**Suggestion:** keep – make into 2 separate questions for nutrition and pa
20. Were there times when you did not try the suggested nutrition and/or physical activity changes because something got in the way?

☐ No
☐ Yes, sometimes
☐ Yes, often

If yes, please share what you experienced:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Intention of question: EconAccessibility / barriers to changes

Usefulness to QI: may identify barriers that HCPs may help reducing but may not be changeable either

Issues from CI:
Clarify: (word) read several times, seemed to change meaning a few times e.g. "Yes, did try a little of all the foods available at Easter", then re-read and seemed to understand as intended.
AK thoughts: maybe add something to no response? E.g. No, nothing got in the way

Suggestion: keep – make into 2 separate questions for nutrition and pa

21. How has working with the team members on nutrition and/or physical activity helped you better manage your health?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Intention of question: Pt activation – action on goals

Usefulness to QI: get sense of what is working well

Issues from CI:
comments: "Oh! Well this is what I wanted to say" then proceeded to list improvements noticed.

Suggestion: keep

22. What would improve your experience of this service? Are there nutrition and/or physical activity services that you think should be added, removed, or changed?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Intention of question: Services provided – suggest improvements (additional services)

Usefulness to QI: offers pts input on what would improve experience and new services that could be offered

Issues from CI:
Formatting: wanted this in 2 questions 'you have the space for it';
Additional comments: didn't really answer first questions; read both questions but only answered second.

Suggestion: Change to one question, allow it to be as broad as possible – modify second part of this question slightly.

Thank you! Your feedback is important.
It will be used to make improvements to services.

Length of questionnaire: "I don't find it too long"; "It's ok. it was shorter than I thought it was going to be?"; length fine; nothing too intrusive or personal; length ok 'not too long'; length ok.
Appendix Q: Questionnaire – May 2014 version

Patient experience questionnaire:
(insert program/services name here)

Insert information about the service/program being evaluated. (max 80-100 words)

We are interested in your experiences using lifestyle services through this clinic (or program name). You are being invited to take part in this survey because you have met with one or more team members through your family doctor’s office (or program name) to change your nutrition and/or physical activity habits.

Team members may include the dietitian, exercise specialist, doctor, nurse, or other people working in the clinic. Answering these questions will help us to improve these services.

Before you answer, please remember that:
• You can choose whether to fill in the survey or not.
• You can skip any question you are not comfortable answering.
• No one will know who answered this survey.
• There are no right or wrong answers.

All questions are about: (insert program/service name)

1. How did you find out about this service?

☐ A doctor, nurse practitioner, nurse told me
☐ Another healthcare professional told me
☐ Advertised in the office
☐ A friend told me
☐ Other: ______________________________

2. How did you access this service?

☐ Referred by doctor, nurse practitioner, or nurse
☐ Referred by other healthcare professional: _______________________
☐ I referred myself
☐ Other: ______________________________
3. How would you rate the importance of this service to your health? Please circle.
(0 = not important at all, 10 = extremely important)

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

4. How long did you wait from the time you were referred to the time you had your first appointment?

☐ Less than 2 weeks
☐ 2 to 4 weeks
☐ 5 to 8 weeks
☐ More than 8 weeks
☐ I don’t know

5. Did you stop attending before the program finished?

☐ No
☐ Yes

If Yes, please share what influenced you to stop attending appointments before the program finished.

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

6. Did you know what to expect from the nutrition and/or physical activity services in terms of how many appointments you would have, what you would learn, and the amount of support you would be offered?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

Comments:
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

7. How would you describe the program length to support your lifestyle changes?

☐ Too short
☐ Just right
☐ Too long
8. Were there times when you found it difficult to get to nutrition and/or physical activity appointments because of the additional costs or time it involved (e.g. childcare, parking, transportation, work schedule, other commitments)?

☐ Never  ☐ Rarely  ☐ Sometimes  ☐ Often  ☐ Very often

Comments:

________________________________________________________________________________________

Questions 9-16 relate to ALL the different people (team members) that you saw through this program to support nutrition and/or physical activity. Please add any comments you have for the questions below:

9. Were you able to contact a team member about your nutrition and/or physical activity when you wanted to?

☐ Yes, definitely  ☐ Yes, to some extent  ☐ No, not at all  ☐ I did not need to contact a team member

10. How often did the team members explain things to you in a way that you clearly understood?

☐ Always  ☐ Usually  ☐ Sometimes  ☐ Rarely  ☐ Never

11. Were you comfortable sharing personal information with the team members?

☐ Yes, definitely  ☐ Yes, to some extent  ☐ No, not at all
12. How often did the team members treat you with courtesy and respect?

☐ Always
☐ Usually
☐ Sometimes
☐ Rarely
☐ Never

13. Did the team members consider your personal situation (lifestyle, income, traditions, and culture) when making nutrition and/or physical activity recommendations for you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

14. Did you have confidence in the information about nutrition and/or physical activity that the team members gave you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

15. How often were you told different things (that didn’t make sense together) about nutrition and/or physical activity?

☐ Often
☐ Sometimes
☐ Never

16. Have the team members provided the information and support you need to make changes to your nutrition and/or physical activity?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not really
☐ No, not at all
☐ No, I have not needed information and support
17. Were you involved in setting nutrition and/or physical activity goals to address the health issues that matter to you?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not at all

18. How confident are you that you can maintain the changes in your nutrition?

☐ Totally confident
☐ Very confident
☐ Moderately confident
☐ A little confident
☐ Hardly confident at all

19. How confident are you that you can maintain the changes in your physical activity?

☐ Totally confident
☐ Very confident
☐ Moderately confident
☐ A little confident
☐ Hardly confident at all

20. Were there times when you did not try the suggested nutrition changes because something got in the way?

☐ No
☐ Yes, sometimes
☐ Yes, often

If yes, please share what you experienced:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
21. Were there times when you did not try the suggested physical activity changes because something got in the way?

☐ No  
☐ Yes, sometimes  
☐ Yes, often

If yes, please share what you experienced:

__________________________________________________________________________________________

__________________________________________________________________________________________

22. How has working with the team members on nutrition and/or physical activity helped you better manage your health?

__________________________________________________________________________________________

__________________________________________________________________________________________

23. Are there services that you think should be added, removed, or changed?

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

Thank you! Your feedback is important. It will be used to make improvements to services.