Participatory Research for Chronic Disease Prevention in Inuit Communities

Joel Gittelsohn, PhD; Cindy Roache, BRec; Meredith Kratzmann, MA; Rhonda Reid, BHEc; Julia Ogina; Sangita Sharma, PhD

Objective: To develop a community-based chronic disease prevention program for Inuit in Nunavut, Canada. Methods: Stakeholders contributed to intervention development through formative research (in-depth interviews (n=45), dietary recalls (n=42)), community workshops, group feedback and implementation training. Results: Key cultural themes included the perceived healthiness of country foods, food sharing, and importance of family. During community workshops, key problem foods for intervention were identified as well as healthier culturally and economically acceptable alternatives for these foods. Behaviors for promotion were identified and prioritized. Conclusions: This approach resulted in project acceptance, stakeholder collaboration, and a culturally appropriate program in stores, worksites, and other community venues.

Key words: formative research, community participation, food store intervention, chronic disease, Inuit

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This paper describes the development of the Healthy Foods North (HFN) program, a community-based intervention to reduce risk factors for chronic disease in Inuit communities in the Canadian Arctic. We present a model for integrating formative research findings and participation by community members to develop a culturally appropriate intervention.

Formative research combines qualitative and quantitative methods to describe the beliefs, perceptions, and behaviors of a specific group and does so within a specific sociocultural, environmental, and economic context. The resulting data allow for the development of intervention strategies and materials that are tailored to the group’s needs and preferences and to the setting in which they live.1-4 Formative research is a common first step in developing interventions to modify human health behavior.3,5-7 Furthermore, conducting formative research can build trust, collaboration, and acceptance of the project by community members and other key stakeholders.

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Community participation in the planning, implementation, and evaluation of community-based interventions has long been considered an effective strategy for implementing successful programs, particularly among indigenous populations. Historically, research conducted in these populations has involved outsiders carrying out their research with limited input from community members. A significant number of research projects have not directly benefited the communities in which they were conducted and, in some cases, brought harm and stigmatization, causing some communities to become suspicious of research efforts. Establishing trust and working in partnership with communities to design projects is crucial, especially when designing and implementing community-based interventions.

Successful community-based interventions targeting indigenous peoples of North America have emphasized the importance of community participation, collaboration between researchers and the community, and incorporation of local culture. However, the literature provides little guidance for the best ways of incorporating these components in intervention development, especially in regard to the use of cultural information. One intervention with First Nations (aboriginal community or band recognized by the Canadian government) emphasized the importance of interviews for understanding local perceptions and cultural concepts, but the process of using this information in the intervention was not presented. A paper describing participatory research for a diabetes intervention targeting First Nations children presented general principles for implementing participatory research with no specific guidelines for intervention development. A third paper on an intervention targeting American Indian families presented a participatory research model that included culturally specific intervention development, but did not include information on the incorporation of participation and cultural information. No literature has been published on participatory methods used to develop health programs among Inuit.

In an effort to address the gap in the literature, this paper describes the process of integrating formative research with community stakeholder participation in the development of the HFN program for the Inuit population of Nunavut. The process took place in 5 phases, culminating in program implementation and evaluation.

**Background**

The Inuit are the original inhabitants of the Arctic regions of Canada, Greenland, Russia (Siberia), and the United States (Alaska). Historically, Inuit have depended heavily, if not exclusively, on country foods (their term for locally harvested and gathered foods), including fish, wildfowl, and both marine and terrestrial mammals. Some micronutrients and fiber were obtained through seasonal consumption of berries or the stomach contents of terrestrial mammals. Country foods continue to be important today, preferred for reasons of taste, healthiness, cost, and identity maintenance. Modern Inuit populations in the Canadian Arctic live in settlements (or hamlets). Income-generating opportunities are few, leading to high levels of unemployment and underemployment in the communities. Most households receive government assistance.

The average life expectancy for Inuit and Inuvialuit populations in the Canadian territories of Nunavut and the Northwest Territories (NWT) is more than a decade lower than the national average. Levels of obesity in these territories increased up to 88%, far more rapidly than the national average in the last 10 years. These changes appear related to dietary and lifestyle transitions occurring for this population, including a replacement of traditional foods with store-bought foods. Growing levels of obesity and physical inactivity put Inuit populations at increased risk of mortality and developing type 2 diabetes, cardiovascular disease, and cancer. Current levels of diet-related chronic diseases such as diabetes and heart disease are equivalent to or higher than Canadian national levels, whereas certain types of cancers far exceed national averages.

Environmental changes occurring in concert with individual behavior change strategies have been identified as a promising approach for preventing obesity. Recent work with food stores in low-income populations has shown this to be an effective means of changing the food en-
vironment and improving diet and diet-related behaviors. The HFN program is a community-based intervention that was developed to address the need for an effective environmental intervention to reduce obesity and chronic disease risk in Inuit peoples in Nunavut, Canada. The program aims to alter the existing environment by bringing healthy foods to stores and promoting them through in-store and mass media promotions, including posters, flyers, interactive sessions, educational displays, radio and television announcements. Additional components of the intervention seek to increase physical activity through promotions in worksites and other community groups.

The intervention plan is based on a conceptual framework encompassing components of behavior change from the social cognitive theory (SCT) and social ecology. SCT includes factors at the individual and environmental levels, including behavioral capability, observational learning, self-efficacy, outcome expectations and expectancies, reinforcement, reciprocal determinism, and physical factors external to the person. Ecological models emphasize the influences of social-environmental and physical-environmental factors and the interplay of these factors across multiple levels.

The HFN program is being implemented in 2 communities in Nunavut, Canada. Community A is a regional center, with approximately 1500 people. It is considered a very transient community and has a large population of non-Inuit people due to the presence of regional government offices and other employment opportunities. It is also home to many Inuit who have come for educational/training or employment opportunities. In addition, many Inuit who formerly lived in outpost camps and smaller communities have settled there. The community has 2 food stores, the Northern Store and the Co-op. There is also a small fast food restaurant with take-out food available and one restaurant in a local hotel. A meat processing plant is located in the community, which processes government inspected musk ox and fish products for local purchase and export. The unemployment rate is 9.7%.

Community B has a population of over 800 people and is located at the heart of the Northwest Passage. The community has a Northern Store and Co-op. In addition, the local Hunters and Trappers Organization provides country foods. The rate of unemployment in Community B is 28.1%. The main employers are the hamlet, the stores, and an Inuit arts and crafts manufacturer. Hunting is still a very common part of daily life in the community.

**METHODS**

**Project Development**

Project development was based on 3 primary components: (a) formative research, which allowed for the identification of the population's needs and preferences and provided a context for understanding food and physical activity decisions; (b) stakeholder participation, which guided the development of intervention components and established collaboration; and (c) incorporation of key approaches from the 2 theoretical frameworks. Figure 1 charts the phases of intervention development and points of participation by project stakeholders. Project development began with formative research during which community leaders, community members, health and social service staff, representatives from local community organizations, and store staff were interviewed in depth regarding their perspectives and concerns about health. The program-planning phase then involved these same stakeholders in the development of an intervention plan and intervention materials through community workshops.

In the refinement and feedback phase, Inuit and non-Inuit project staff integrated ideas generated by stakeholders and created a listing of proposed intervention materials. These ideas were then developed into visual materials by an Iqaluit-based graphics company in both English and the local community language. Draft materials were iteratively presented to stakeholder groups to determine appropriateness and then revised. In the training phase, the intervention plan, materials, and process of implementing the intervention were presented to stakeholders for a final round of feedback. Throughout program development and implementation, ongoing partnerships with food stores and community organizations were critical. Discussion of the key theoretical constructs is woven into the detailed presentation of phases below.
Phase 1: Initiation and Formative Research

Planning for the HFN program was initiated by representatives from the Government of Nunavut Department of Health and Social Services – who invited 2 of the coauthors (JG, SS) for a visit to the study areas in April 2005.

A 6-month-long formative research phase was initiated in July 2005 and focused on understanding the sources of food available to community members, cultural norms around food practices, local concepts of healthy and unhealthy foods, shopping habits and factors affecting food purchasing, and identification of store management practices and factors motivating their decisions. It also provided an opportunity to present intervention ideas to stakeholders and to ascertain their interest and suggestions for successful implementation.

In-depth interviews conducted with community leaders (n=7) focused on health and nutrition in the community, approaches to influencing dietary habits of community members, and intervention feasibility. Interviews with community members (including 4 elders) (n=23) addressed country food harvesting and food shopping habits, including where people shop, what they buy, and what influences purchasing decisions. Store managers and staff (n=8) were interviewed about store management procedures, such as ordering and stocking foods. They
also discussed the feasibility of a store-based intervention and potential intervention strategies. Interviews with health staff (n=7) focused on community health issues, community programs, and options for addressing health issues. All interviews were conducted by a Canadian graduate student, trained by the first author in exploratory interviewing approaches (e.g., probing, avoiding leading questions), note-taking, and writing up interviews. Lectures adapted from a qualitative research course taught by the trainer, demonstrations, role-play, observation of interviewing style, and review of interview transcripts from previous interviews were the primary training methods used over the 3-day training period.

Forty-two single 24-hour dietary recalls were collected by 2 interviewers who were trained for one week with observed practice sessions including at least one complete 24-hour recall on a community member. Demonstrations, role-play, and observation were the primary training methods used. A standard manual of procedures was developed and strictly followed by the interviewers.

Table 1
Food Sources and Reasons for Using or Not Using Specific Sources

<table>
<thead>
<tr>
<th>Source</th>
<th>Common reasons for using</th>
<th>Common reasons for not using</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Store</td>
<td>Fresh food, good quality, more variety</td>
<td>Expensive</td>
</tr>
<tr>
<td>Co-op Store</td>
<td>Lower prices, member, loyal to community-owned and - operated business</td>
<td>Not as fresh, poorer quality, foods beyond expiry date</td>
</tr>
<tr>
<td>Travelling</td>
<td>Cheaper to buy food in the south, even with charge for extra weight on the planes, certain foods are not available in stores in the community</td>
<td>Do not travel often</td>
</tr>
<tr>
<td>Barge Order</td>
<td>Cheaper to buy in bulk, lower freight, cheaper than stores</td>
<td>Have to order on time, large sum of money needed at once</td>
</tr>
<tr>
<td>Food Mail</td>
<td>Cheaper than stores, may be better quality</td>
<td>Complicated, poor quality, don’t necessarily get what you order, requires a credit card and car, never heard of it</td>
</tr>
<tr>
<td>Hunting and Harvesting</td>
<td>Prefer country food, grew up on country food, body craves it and needs it, healthy for you, healthy for children, enjoy going out on the land, cheaper than store-bought food, concerned about mad cow and bird flu</td>
<td>Don’t hunt as much, working and don’t have time to hunt regularly, don’t have a snow mobile or other equipment for hunting, no hunter in household, concerned about contaminants</td>
</tr>
<tr>
<td>Country food provided by hunter, store, Hunters and Trappers Organization</td>
<td>Don’t have own country food, can’t access certain country foods in this community, ran out of own country food</td>
<td>You just don’t pay for country food, too expensive</td>
</tr>
<tr>
<td>Quick Stop (Community A only)</td>
<td>Convenient, nice treat for children or on rare occasions, kids like it</td>
<td>Junk food, not good for you, fattening food</td>
</tr>
</tbody>
</table>
Respondents were adult Inuit community members, aged 19-87. The time of consumption and the type of food or drink being consumed including brand name were recorded, along with any additions such as sugar in tea and coffee. A range of 3-dimensional food models was carefully selected with the help of local staff to represent different portion sizes of foods usually consumed. An additional list of questions was included to prompt for easily forgotten foods such as dried meats, fats, sweets, and snacks.

All interviews in Community A were conducted in English except for a few with older respondents who spoke only their native language. In these situations a local translator was used. In Community B almost all interviews were conducted in the local language (Inuktitut) although the bilingual interviewer recorded in English. The interviewers collected 24-hour recalls on different days of the week and the weekend.

The research was approved by the Nunavut Department of Health - Health and Social Research Review committee. Informed consent was obtained prior to each interview. Most interviews were tape-recorded and transcribed verbatim. Some interviews were not recorded, in which case the interviewer took detailed notes that were later transcribed. Qualitative data were analyzed and managed using N6 QSR NUD*IST, a textual data management software program. Interviews were analyzed using the constant comparative method.42

**Summary of Formative Research Results**

In both study communities, people get food from various sources, including food from the land and ocean (country foods), local store-bought food, shipped food (eg, Food Mail, barge orders, food bought while travelling), and food that is shared. Table 1 summarizes the different common sources of food and the reasons respondents gave for preferring one food source over another. All interviewees used more than one source and indicated that their usage patterns vary depending on the time of year.

Community leaders and health staff noted that the ability to access country food is considered integral to physical and mental health at both the individual and community levels. However, they noted several barriers or challenges they believe prevent people from eating a healthy or healthier diet, including the cost of food and basic hunting supplies, lack of skills to prepare store-bought foods, lack of education about healthy eating and budgeting, food availability, change in animal migration patterns, and the impact of working full time.

Several core cultural values with respect to food emerged from the interviews, including respecting and honoring animals, not wasting food, sharing food, and enjoying food with family and community. Country foods are viewed as healthier than store-bought foods, largely due to the energy they provide. Respondents reported feeling “lazy” and “tired” and “unfulfilled” when they do not eat country foods. Some respondents indicated that if they are going to be travelling somewhere for a few days they will bring country foods with them so they will not be without it for too long. Respondents described unhealthy foods as “junk food” and “fast food,” rather than referring to specific qualities (eg, high sugar, high fat). Unhealthy foods are sugary foods that “rot your teeth,” processed foods, and prepackaged foods. Commonly mentioned examples of unhealthy foods were chips, pop, chocolates, candies, juice crystals, and fast food or “stuff you just put in the microwave.”

Food sharing is a core cultural value and was mentioned by most respondents. In the traditional Inuit way of life, food was not gathered for individuals or families alone, but also for the benefit of the community. Respondents described 4 ways that food is shared today: according to traditional practice, by communal responsibility, via solicitation, and through exchange. When there is great abundance, food will commonly be shared with relatives, but less commonly with friends or neighbors. It is common for relatives or other community members to request food from a household known to order Food Mail or receive barge shipments. Community members will stop or reduce the amount of food that they ship through these channels because of the cost of having to share it with others and lack of credit.

Food store managers expressed their strategies for deciding which foods to stock in local stores. Profitable foods tend to have a long shelf life and weigh less, such
as dry soup mixes, instant ramen noodle soups, dry rice and pasta, soft drinks (locally referred to as “pop”), chips, candy, and frozen pizzas. Several key challenges were noted to stocking foods, including adequate storage space. In the winter, foods may become frozen in transit; this affects fresh produce and dairy products in particular, as well as canned goods. The dating on food creates challenges even for foods that last longer. Some foods have “best before” dates that are less than one year.

Foods are stocked based on need and customer request. The decision to stop stocking an item is usually up to the manager. Items will not be restocked if they do not sell. New items are tried based on customer requests and the availability of new items (eg, a new type of cereal). All stores rely on 3 main strategies to promote foods: monthly flyers, in-store specials, and shelf-talkers (shelf labels that project outwards into the shopping aisle). There was strong support from local store managers to promote healthy foods. Taste tests and cooking demonstrations were considered great ways to build consumer awareness and support store sales. The store managers also strongly supported the idea of using the displays on the aisle ends to promote certain healthy foods. Managers felt that visual promotional materials, such as posters, brochures, and shelf-talkers would be effective. Using the local radio station and cable channels was also mentioned as important avenues for reaching the community.

**Phase 2: Community Workshops**

The formal intervention planning phase began with two 2-day community workshops in September 2006. The objectives of these workshops were to bring together project stakeholders and develop the overall approach of the project through the process of selecting key foods and behaviors, identifying the best media, choosing key messages, and developing specific intervention materials.

A total of 23 people participated in the 2 workshops, the majority of whom were Inuit (83%). Participants included elders, community leaders, representatives of community health programs, store managers, and other community members, representing multiple aspects of the food environment. As a means of building rapport and establishing respect for participant ideas, the initial task was to allow each participant to talk freely about his or her concerns regarding food and health. Comments were summarized on flip charts and posted on the walls, further validating opinions and concerns. Following a brief presentation on formative research findings, participants were led through a series of activities focusing on specific aspects of the intervention, including identification of problem foods, healthier alternatives for these foods, behaviors to promote, messages to convey select promoted foods and behaviors, and channels to convey the messages. Each topic was introduced with a brief description followed by a group session and prioritization activity during which the group brainstormed ideas and then voted for their top priorities. A summary of the results of each activity is described below.

**Problem foods.** Participants first brainstormed to get a list of all foods (39 and 24 foods in communities A and B, respectively) they considered problematic and contributing to poor health in their communities. Participants were then given a limited number of votes and asked to place their votes (sticky dots) next to the foods they considered most important to address in the program. This ranking was then combined with foods contributing the most energy to the diet based on the dietary recalls to get ranking of the key foods to be addressed in the overall HFN program (Table 2).

**Promotable foods.** Community workshop participants were then challenged to match the top 5-6 problem foods with healthier alternatives that would be economically and culturally acceptable. Suggestions were again recorded on flip charts and mounted for easy inspection. A second round of voting identified the most favored alternative foods for promotion for each of the top problem foods. For example, soft drinks were a top-mentioned problem food in both communities. In community A, the top-ranked alternatives to soft drinks for promotion were ice water, river water, and water with lemon and tea whereas in community B, the top-ranked alternatives were frozen juices, bottled water, and diet soft drinks. New foods were selected to be stocked in local stores as a means of changing the food environment and to be promoted in stores and in other community settings.
Targeted behaviors. Workshop moderators suggested that behaviors be chosen based on how commonly they are performed, their impact on diet, and their potential changeability. The 2 workshops generated an extensive list of behaviors, which were then voted on and grouped by similarity of topic. Overall the top choices in rank order were promoting healthier cooking methods at home, eating together as a family, shopping with a list, labeling healthy foods in stores, reducing prices of healthier foods, promoting the consumption of country foods, and having children help with cooking at home. Selection of behaviors for promotion represents the second main intervention component of SCT.

Messages and channels. Participants developed specific messages that matched the priority foods and behaviors and voted on best messages. Possible channels used to reach various audience segments were identified, and their feasibility and potential impact were discussed. Addressing the personal/psychosocial component of SCT, messages and channels selected were intended to impact on self-efficacy, behavioral intentions, and outcome expectations. In particular, an emphasis was placed on enhancing the self-efficacy of community members for making healthy food choices and preparing foods in ways that would lower total energy density, while improving nutrient density.

Phase 3: Intervention Refinement and Feedback

During phase 3 (September 2006-March 2008), project staff and investigators reviewed the foods, behaviors, and messages generated during the workshops and reduced the total list to a manageable number. Selection was confirmed by identification of the food or behavior in the formative research, extent of its impact on diet (from dietary recalls), and likelihood that a healthier alternative food or behavior would be accepted.

Once foods and behaviors were selected, intervention phases and approaches were
determined. Foods and behaviors were matched, and specific materials were planned. Project staff also met with stakeholders and led small group discussions to generate feedback. Several topics were addressed by stakeholders, including the acceptability of promoted foods, the feasibility of implementing intervention components, and the cultural relevance of specific intervention materials. Through continued stakeholder and project staff feedback, the intervention plan was modified numerous times. Study investigators met on several occasions to plan intervention strategies.

During this phase, cultural themes and a common motif to be carried throughout the intervention were developed. First, the importance of family and respect of elders were identified as important aspects of Inuit/Inuvialuit culture from formative research, the workshops, and the literature.16-19 These themes were emphasized with a family motif whose characters modeled positive behaviors, a function of the observational learning component of SCT. Second, improvement of self-efficacy for food label reading was emphasized throughout the intervention due to identified needs. Third, an emphasis was placed on food sharing as a key cultural theme – and in families getting food, preparing and cooking it together. The cultural theme of intergenerational sharing of knowledge was woven into many of the materials and the narrative stories. The materials reinforced key outcome expectations related to the practice of promoted behaviors, including reduced risk for illness. Fourth, we acknowledged and supported the deep emphasis on the healthiness of country foods by focusing many of the intervention materials on ways to prepare these foods and combine them with store-bought foods. Finally, the importance of cost was addressed by the selection of affordable foods for promotion and the development of intervention materials that specifically demonstrate the low cost of healthier foods.

These themes were woven into the visual materials used for the program, a combination of posters, educational displays, cable television ads, shelf labels, and flyers. An Iqaluit-based graphics firm created drawings for the family motif and used the characters in subsequent materials. Completed materials were presented to project stakeholders throughout the refinement and feedback phase.

In addition, a series of radio narratives were developed that incorporated the motif characters and recordings made to be played over the radio or local cable television station. Worksites and other natural groupings of people were identified for implementation of focused intervention efforts, including coffee station “makeovers” and organization of pedometer challenges and related physical activity promotion activities. All of these intervention components addressed and reinforced key messages and themes simultaneously.

In this period as well, collaborative relationships were established with the North West Company and Arctic Cooperatives Limited, the 2 food store chains that are present in both the intervention communities. Based on the formative research and community workshops, it became evident that a partnership needed to be developed with the North West Company main office, in addition to local store managers, as many stocking decisions were made at the headquarters level, and support from the main office would be required to enact recommended changes. From April-July 2008, the HFN program materials were piloted in 2 Inuvialuit communities in the Northwest Territories. This experience enabled us to refine our intervention strategies for the work in the 2 Nunavut communities.

Phase 4: Interventionist Training
During the final phase of intervention development, a 3-day training was held in August 2008. Attendees included 4 interventionist trainees from the 2 intervention communities, a local community health representative, members from other community organizations, 2 project coordinators, and store staff. The training was led by the first author (JG). The training reviewed in detail each phase of the program, presented the materials, and provided skills needed to implement the program. The formative research, community workshop results, and conceptual frameworks driving the program were also included in the training. Participants offered suggestions and comments on how to improve the materials and implement the intervention, and suggested modifications were incorporated. At the end of the training, issues of sustainability and dissemination of the
program were discussed.

**Phase 5: Program Implementation and Evaluation**

HFN was initiated in Nunavut in September 2008. The 14-month program will be evaluated in terms of impact and process, using a quasi-experimental design. Two communities (A and B) are receiving the intervention, whereas a third (community C) serves as a comparison. Impact assessments will compare changes pre- and postintervention between a random household-based sample of consumers and stores in the intervention and comparison communities. The Adult Impact Questionnaire will assess food purchasing, food preparation, behavioral intentions, knowledge, self-efficacy, and health beliefs and attitudes during the postintervention phase and will also assess customer exposure to intervention materials. The Food Frequency Questionnaire will collect individual dietary intake over the past 30 days to assess impact on diet.43 Process evaluation instruments will be administered continuously throughout the intervention in order to evaluate the implementation of various intervention components.

**DISCUSSION**

The HFN program was developed on the basis of formative research findings and the contributions of project stakeholders during multiple phases of intervention development. Previous intervention programs targeting specific cultural groups have demonstrated the effectiveness of using these sources of information to guide intervention development. In a 5-a-day program promoting fruit and vegetable consumption in North Carolina, intervention success was partially attributed to the use of qualitative research for the development of culturally sensitive intervention components.5 The use of formative research in intervention development has also contributed to the success of HIV prevention programs.6 In our own work, we have used this model successfully with American Indians,44 First Nations,45 and an urban African American population.46

Many of the themes identified in the formative research are common to other indigenous populations. The perceived healthiness of traditional foods over store-bought foods has been found among the Oji-Cree,47 Ojibway,45 Apache,44 and Pacific Islanders.48,49 In the Inuit setting, the still relatively high reliance on and availability of country foods provide both opportunities and challenges to working in these communities. We found strong support for a return to traditional family values and family styles of eating – and this was associated with a desire to increase country foods in the diet. However, among younger respondents, there is less consumption of these foods and lack of familiarity with their preparation. Solutions for improving diet can include country foods, as we have done in HFN, but cannot be the sole emphasis of nutrition programs to reduce risk for chronic disease.

Successful interventions targeting indigenous communities have emphasized the importance of community participation and collaboration,12-14 but specific ways of achieving collaboration and consensus have not been well described. The development of HFN purposefully emphasized stakeholder involvement through formative research, small group presentations, community workshops, and training as a means of understanding the needs of the target population, addressing them in a culturally relevant manner, encouraging participation, and building consensus among stakeholders. Community workshops were a particularly valuable means of building participation and identifying strategies for the HFN program.

The model for integrating formative research and stakeholder participation in intervention development presented in this paper may be applied in similar settings where understanding the context of the intervention and cultural differences of the target group is important for intervention success.

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