

Check It Out/ À voir:

**An Assessment of Young Women's
Interest in and Knowledge of the
Impact of Alcohol, Nutrition and
Physical Activity on Breast Health**

**Developed by Parent Action on Drugs in collaboration with youth and health
promotion partners in English and French communities in Ontario
October, 2006**

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October, 2006

Check It Out: An Assessment of Young Women's Interest in and Knowledge of the Impact of Alcohol, Nutrition and Physical Activity on Breast Health

Executive Summary

Check It Out was a project to understand young women's issues and needs regarding lifestyle factors which affect breast health and how to mesh these needs into language, messaging and behavioural goals that would be acceptable to them in order to reduce their risks for breast cancer and promote breast health.

1. Project Outline

In 2005, the Canadian Breast Cancer Foundation—Ontario Chapter provided funding to Parent Action on Drugs to identify whether or not young women in Ontario, ages 16-20, in both English and French-speaking communities, were aware of the links between the risk factors for a healthy lifestyle and breast cancer. The project also examined what these young women would recommend to support increased awareness of these links with their peers.

Parent Action on Drugs (PAD) is a provincial organization addressing the issues of substance use among youth. PAD enhances the capacity of parents, youth and communities to promote an environment that encourages youth to make informed choices about alcohol and other drug use.

Emerging research indicates that alcohol use can be a risk factor for breast cancer along with unhealthy eating patterns and a lack of physical activity. Often these risk factors are clustered in young women in the ages of 16-20.

The Canadian Breast Cancer Foundation—Ontario Chapter funded PAD to identify effective tools and supports to access information about these issues from these young women in a timely manner.

2. Partnerships

PAD's initial proposal identified the need for a partnership for guidance and support. Often there is little cross-over between health promotion initiatives addressing different risk factors. Because of the nature of this project, PAD needed input from partners whose expertise lies in addressing physical activity and healthy eating issues with young women. Second, PAD's paradigm is to work with the target age group as partners in developing and delivering programs. Therefore young women in the age group were sought out to be active partners. Third, as one of the project's objectives was to learn about these issues within both English and French-speaking communities in Ontario, local support from two identified communities was needed. Finally, it was essential to work directly with a partner who could provide expertise on the subject area of breast cancer; the Canadian Breast Cancer Network, a national network of breast cancer survivors, was the expert partner in this area.

The partners in this project were:

Young women 16-20; Canadian Breast Cancer Network; Niagara Regional Public Health and Regional Health Services; Sudbury and District Centre for Addiction and Mental Health; Physical Activity Resource Centre, a project of the Ontario Physical and Health Education Association; Nutrition Resource Centre, a project of the Ontario Public Health Association;

Centre for Addiction and Mental Health, Social, Prevention and Health Policy Research Department; FOCUS Resource Centre; Ontario Drug Awareness Partnership; Family and Youth Therapy, Centre for Addiction and Mental Health

3. The Method

Between October 2005 and March 2006, focus groups were held with young women in Niagara (in English) and in Sudbury (in French). The focus groups resulted in the development of an online survey tool to assess young women's knowledge of and interest in lifestyle factors and breast cancer. The tool was designed to encourage answers to as many open-ended questions as possible. This tool was then tested by youth advisors to the project, then disseminated and promoted to young women across the province from May through July, 2006.

By July 31, 2006 the online survey was closed. The site received 355 qualified respondents with 314 in English with and 41 in French.

These results were analyzed by the project partners and key findings identified.

4. Key Findings

- Young women ages 16-20, in both English and French-speaking communities are drinking often, are not as physically fit as they think they should be and are not eating as well as they think they should.
- While these young women believe that they will change in 5 years to improve their eating and physical activity patterns, the majority do not think they will change their drinking patterns because, "everything causes cancer anyway".
- They have little to no knowledge about the links between risk factors and breast cancer, although more knew about these links for healthy eating than either of the other factors.
- They are interested in having this information because the majority said they try to be as healthy as they can.
- They have very interesting ideas about environmental support strategies which would increase their level of physical activity and help them eat in a healthier way.
- They also have ideas about effective tools and spokespeople for communicating the concept of modifying lifestyle to reduce risks. Spokespeople included breast cancer survivors, peers and mothers. The key difference from a cultural perspective was identified here with the French-speaking respondents identifying teachers and curriculum support as very important resources, above peers and mothers.
- Respondents with a close relative who had breast cancer reported drinking slightly more than those who did not, but did not differ from the mainstream group otherwise.

- The young women who responded to the survey would be interested in having information which would reduce their risks for breast cancer if it were presented in a way that gave them options within their current lifestyles.

5. Recommendations

- Disseminate the results of this project to health promotion specialists in Ontario.
- Develop a communication plan for young women to offer strategies to reduce their risks and increase breast health.
- Continue with a “cross-factor” partnership with specialists in specific risk factors in order to address risks that cluster in the target group.
- Continue the involvement with young women as advisors in this partnership.

À voir : Une évaluation de l'intérêt des jeunes femmes à l'égard de l'incidence de l'alcool, de la nutrition et de l'activité physique sur la santé du sein, et de leurs connaissances en la matière.

Résumé

À voir est un projet qui avait pour objectif de favoriser la compréhension des besoins des jeunes femmes et des questions qui les touchent au chapitre des aspects du mode de vie ayant une incidence sur la santé du sein et de formuler ces besoins sous forme d'objectifs convenables en matière de vocabulaire, de message et de comportement, dans le but de réduire le risque de développer un cancer du sein et de favoriser la santé du sein.

1. Aperçu du projet

En 2005, la section ontarienne de la Fondation canadienne du cancer du sein a accordé du financement à Parent Action on Drugs (PAD) dans le but de savoir si les jeunes Ontariennes de 16 à 20 ans de communautés anglophones et francophones connaissaient ou non les liens entre les facteurs de risque d'un mode de vie sain et le cancer du sein. Ce projet s'est aussi penché sur les suggestions de ces jeunes femmes dans le but d'appuyer une plus grande sensibilisation à l'égard de ces liens auprès de leurs camarades.

PAD est un organisme provincial abordant les questions liées à la consommation d'alcool et de drogues chez les jeunes. Il renforce la capacité des parents, des jeunes et des communautés dans le but de promouvoir un milieu qui encourage les jeunes à prendre des décisions éclairées sur la consommation d'alcool et d'autres drogues.

Des recherches émergentes indiquent que la consommation d'alcool pourrait être un facteur de risque du cancer du sein, tout comme les mauvaises habitudes alimentaires et un manque d'activité physique. Souvent, ces facteurs de risque sont présents en grand nombre chez les jeunes femmes de 16 à 20 ans.

La section ontarienne de la Fondation canadienne du cancer du sein a donné à PAD le mandat de demander à ces jeunes femmes de cibler des outils et des mécanismes de soutien efficaces permettant d'avoir accès à des renseignements sur ces enjeux, et ce, en temps utile.

2. Partenariats

La proposition initiale de PAD ciblait le besoin d'un partenariat visant orientation et soutien. Souvent, il y a peu de liens entre les initiatives de promotion de la santé abordant différents facteurs de risque. En raison de la nature du projet, PAD avait besoin des commentaires de partenaires experts dans les domaines de l'activité physique et de la saine alimentation chez les jeunes femmes. De plus, le paradigme des membres de PAD est de travailler avec le groupe d'âge cible à titre de partenaires de la conception et de la mise sur pied de programmes. Ainsi, on a demandé aux jeunes femmes faisant partie du groupe d'âge d'être des partenaires actives. Enfin, puisque l'un des objectifs du projet était de se renseigner sur ces enjeux au sein des communautés anglophones et francophones de l'Ontario, on a eu besoin de l'appui local de deux communautés ciblées.

Au nom de l'équipe du projet À voir :

Jeunes femmes de 16 à 20 ans ❖ Bureau de santé de la région de Niagara et Services de santé régionaux de Niagara ❖ Centre de toxicomanie et de santé mentale (CAMH) de Sudbury et du district ❖ Centre de ressources en activité physique (PARC), un projet de l'Association pour la santé et l'éducation physique de l'Ontario ❖ Centre de ressources en nutrition, un projet de l'Association pour la santé publique de l'Ontario ❖ Centre de toxicomanie et de santé mentale, Service de la recherche sociale, préventive et en politiques de la santé ❖ Centre de ressources FOCUS ❖ Partenariat ontarien de sensibilisation aux drogues ❖ Programme pour les enfants, les jeunes et leur famille, CAMH ❖

3. Méthode

D'octobre 2005 à mars 2006, on a tenu des groupes de discussion avec de jeunes femmes à Niagara (en anglais) et à Sudbury (en français). Les groupes de discussion ont mené à la conception d'un sondage en ligne permettant d'évaluer les connaissances des jeunes femmes au sujet des aspects du mode de vie et du cancer du sein, et leur intérêt en la matière. L'outil a été conçu de manière à susciter des réponses au plus grand nombre possible de questions ouvertes. Cet outil a ensuite été testé par des conseillères et conseillers des jeunes du projet, puis il a été diffusé et on en a fait la promotion auprès des jeunes femmes de toute la province, de mai à juillet 2006.

Le 31 juillet 2006, on avait mis fin au sondage en ligne. Au total, 355 répondantes qualifiées se sont rendues sur le site, dont 314 étaient anglophones et 41 francophones.

Les partenaires du projet ont analysé les résultats, et ils ont ciblé des constatations clés.

4. Constatations clés

- Les jeunes femmes de 16 à 20 ans des communautés anglophones et francophones boivent souvent, et à leur avis, elles ne sont pas en aussi bonne forme physique et elles ne mangent pas aussi bien qu'elles le devraient.
- Bien que ces jeunes femmes croient qu'elles changeront dans cinq ans afin d'améliorer leurs habitudes au chapitre de l'alimentation et de l'activité physique, la majorité d'entre elles ne croient pas qu'elles modifieront leurs habitudes de consommation d'alcool puisque « de toute façon, tout cause le cancer ».
- Elles ne connaissent pas ou peu les liens entre les facteurs de risque et le cancer du sein, bien qu'un plus grand nombre d'entre elles connaissent les liens ayant trait à l'alimentation saine, plus que tout autre facteur.
- Elles sont intéressées par ces renseignements, puisque la majorité d'entre elles affirment tenter d'avoir un mode de vie le plus sain possible.
- Elles ont des suggestions très intéressantes de stratégies faisant appel aux ressources du milieu qui entraîneraient une augmentation de leur niveau d'activité physique et qui les aideraient à manger plus sainement.

- Elles ont également des suggestions d'outils et de porte-parole efficaces qui pourraient communiquer le concept de modification du mode de vie afin de réduire les risques. Parmi les porte-parole, il y avait des survivantes du cancer du sein, des camarades et des mères. Différence clé sur le plan de la culture : les répondantes francophones ont ciblé les enseignantes et enseignants et les mécanismes de soutien du programme d'études à titre de ressources très importantes, même plus importantes que les camarades et les mères.
- Les répondantes dont une proche avait eu le cancer du sein ont affirmé boire un peu plus que celles dont aucun membre de la famille immédiate n'avait eu le cancer du sein, mais autrement, elles n'ont pas différé du groupe ordinaire.
- Les jeunes femmes qui ont répondu au sondage aimeraient recevoir des renseignements qui leur permettraient de réduire le risque d'avoir le cancer du sein, si ces renseignements leur offraient des options relatives à leur mode de vie actuel.

5. Recommandations

- Diffuser les résultats du projet auprès de spécialistes de la promotion de la santé en Ontario.
- Concevoir un plan de communication à l'intention des jeunes femmes, afin de leur présenter des stratégies leur permettant de réduire les risques et de favoriser la santé du sein.
- Poursuivre un partenariat intersectoriel avec des spécialistes de facteurs de risque précis afin d'aborder les risques qui se présentent en grand nombre chez le groupe cible.
- Poursuivre la participation auprès des jeunes femmes à titre de conseillères, dans le cadre du partenariat.

1. Introduction

1.1 - Purpose of the *Check It Out* Project

The Canadian Breast Cancer Foundation (CBCF)—Ontario Chapter supports projects that fulfill the mission and objectives of the Foundation in the area of health promotion, within a community-based participatory and capacity building framework. This funding is intended to enable communities to undertake projects that will increase their understanding of their breast health needs and their ability to respond effectively to meet those needs. Funding for this project was received under an “Assessment and Planning” grant.

The purpose of this project was to assess young women’s issues and needs regarding lifestyle factors affecting breast health and plan how to meet these in language, messaging and behavioural goals that would be acceptable to them to increase their breast health and reduce their risks for breast cancer.

This project involved young women significantly as key stakeholders to develop and test the tools for this project plus plan for future work in this area. As well, partners concerned with “disparate” lifestyle issues (alcohol, nutrition, physical activity) came together and established a meaningful relationship to share common concerns about chronic disease prevention in general and breast cancer prevention specifically. Finally, the project brought together young women in two cultural communities (English-speaking and French-speaking) to meet with health promotion specialists and work on the development of a tool.

In identified communities (Niagara and Sudbury), young women in the target age range took part in focus groups to identify common risks for a healthy lifestyle specifically as these pertain to alcohol, physical activity and healthy eating. These young women commended the purpose and the method of the project, and indicated that they wanted to have input into such an important topic and were interested in hearing more and being involved further.

The *Check it out* Project sought to meet the criteria for the CBCF—Ontario Chapter in the following ways:

- By building a strong knowledge base of information for the project and for the young women involved: Through the administration of the survey to determine the key information items that are significant to young women, knowledge about risk factors would also be imparted at the same time to those involved in the survey and focus tests.
- By building partnerships: The team members involved in this project had a common interest in lifestyle risk reduction and chronic disease prevention, but had not worked together as a team nor addressed the common concern of breast health and young women. The project increased capacity in the respective health professionals to address this topic in the future.
- By promoting dialogue. The two regions where focus testing occurred have identified that dialogue has begun on this issue. Ways and means of expanding the dialogue in additional communities throughout Ontario should be an outcome of the project.

1.2 The Objectives of the *Check It Out* Project

Project objectives were chosen in order to fit the mandates of both the Project Partnership and CBCF – and which, when met, would move the Project forward in meeting its goals.

The objectives were:

- To assess young women’s (ages 16 to 20) knowledge of and interest in breast cancer prevention and the impact of lifestyle choices about alcohol, nutrition and physical activity on breast health
- To develop partnerships with young women, strengthen the partnership among team members and build partnerships with breast cancer prevention and other health and education professionals
- To promote active dialogue, in French and English, among young women in secondary and post-secondary schools, and health professionals in two regions in Ontario concerning breast cancer prevention and lifestyle issues and choices
- To develop a survey tool with the input of the target population and diverse health professionals and deliver it to 1,000 young women throughout Ontario in Anglophone and Francophone communities
- To analyze the data received, disseminate the results and plan for further capacity-building with communities to develop information sharing among young women to promote breast health

1.3 The Rationale for the Project

Limited knowledge within the health field

In 2004, the member organizations of the Ontario Health Promotion Resource System were tasked by the Ministry of Health and Long-Term Care to collaborate on initiatives to address common risk factors for chronic diseases like cancer.

Following that directive, groups came together to address many chronic disease issues, but there were few if any initiatives which targeted young women and breast health.

Work around breast cancer and young women has mostly dealt with those with breast cancer themselves or those with a mother or other close relative who has or had breast cancer. Awareness of potential risk factors and health promotion of ways to reduce personal risks has not been addressed.

Thus a gap existed in available information around this subject with health professionals.

Limited knowledge among women in Ontario

In a survey completed by the Canadian Breast Cancer Foundation—Ontario Chapter in 2005, it was noted that Ontario women are unaware of many of the risks and preventive practices related to breast cancer. “Despite a high level of breast cancer awareness and

concern, a recent public opinion survey has revealed that women in Ontario have misconceptions about this important health issue in the areas of incidence and risk, signs and symptoms and breast cancer screening practices". (1)

Alcohol as a Risk Factor for Breast Cancer

According to the Ontario Student Drug Use Survey (OSDUS), 2005, young women, ages 16-20 are drinking at levels identified by the World Health Organization as hazardous, meaning already impacting their health. Nearly 30% of girls in Grade 11&12 in Ontario drink at hazardous levels. This number increased significantly between 2001 and 2003 studies and remained constant in the 2005 report. As well, young women are unaware of the risks about heavy drinking beyond impaired driving. (2)

According to the Canadian Addiction Survey, heavy drinking (more than 4 drinks on one occasion for women) is more common among Canadians 18-24 years of age. (3)

In workshops conducted by PAD Trainers, young women have stated that they are unaware that gender put them at increased risk as far as alcohol is concerned for many factors including cancers. PAD Trainers have also learned that young women are interested in having gender-specific information.

The link between alcohol and breast cancer is clear. Babor et al in 2003 identified that "Patterns of drinking also play an important role in the disease burden, being linked to coronary heart disease, motor vehicle accidents, suicide and breast cancer." (4)

Canadian studies: Dr. Kristan Aronson reported in the Canadian Medical Association Journal in 2003 that, "The association between alcohol consumption and breast cancer risk meets several criteria for causality. About 4% of new cases of breast cancer can be attributed to drinking alcohol and in Canada this year (2003), it means alcohol will account for an astounding 700 new cases."(5)

US studies: In 1998, in a pooled analysis of cohort studies, Dr. Stephanie Smith-Warner and her colleagues in Nutrition and Public Health came to the conclusion that alcohol consumption is associated with a linear increase in breast cancer incidence in women over the range of consumption reported by most women. "Among women who consume alcohol regularly, reducing alcohol consumption is a potential means to reduce breast cancer risk."(6)

International studies: In Scotland, in 2003 the Chief Medical Officer of Health warned young women that binge drinking could give them an increased risk of breast cancer later in life. In his annual report to the Scottish Executive, he stated that "drink" could be responsible for as many as 500 cases of the disease each year and this would make it the most common cancer caused by alcohol.(7)

Limitations with the research:

While the link between heavier alcohol use and breast cancer is clear, what is not clear is whether patterns of heavy drinking in adolescence increases the risk for breast cancer pre and post-menopausally, and if so, whether or not the length of time that the pattern is in place impacts on this level of risk.

Reduced Physical Activity and Unhealthy Eating and/or Obesity as a Risk Factors for Breast Cancer

The lines between the lack of physical activity, unhealthy eating patterns, and obesity are blurred and it is often not clear which risk factor is at play when it comes to chronic disease.

Also, linking these risk factors with breast cancer is not as easy as it is with alcohol. There has even been research which suggests that obesity is associated with reduced risk for pre-menopausal breast cancer, a relationship likely due to the adverse effects of obesity on ovarian function in pre-menopausal women. (8) In 2002, a Joint WHO/FAO Expert Consultation identified studies dealing with the risks of other dietary factors (including fat, meat, dairy products, fruits and vegetables, fibre and phyto-estrogens) to be inconclusive and stated that the only nutrition-related risk factor for post-menopausal breast cancer was obesity. (9)

Canadian studies: The Canadian Cancer Society website states that, "Breast cancer is one of the most active areas of study today as researchers tackle the problem from many sides. One such investigation includes studies which focus on the potential role of diet and lifestyle in breast cancer prevention" - and certainly the Canadian Cancer Society acknowledges that of nutrition and physical activity, the latter has the stronger research base to support the links with a risk for breast cancer. "The effects of diet, physical activity and obesity are under study, but research has shown that regular physical activity can help protect against certain types of cancer such as breast and colon cancer. (10) On its website, Health Canada clearly states potential risks for breast cancer and suggestions for ways to reduce the risks. Health Canada includes losing excess weight and maintaining at least a moderate level of physical activity (as well as limiting alcohol intake) as ways to minimize risk of breast cancer. (11)

US Studies: In 1997, The American Institute for Cancer Research (AICR) was very clear in making the connections, estimating that 33-50% of breast cancers could be prevented through nutrition and related lifestyle factors. (12) Another interesting finding from this research indicated that the earlier the patterns of healthy eating are established, the more the risks are reduced. The evidence was listed as probable as opposed to convincing, primarily due to the fact that studies that have found associations are typically case-control, which are not as well-regarded as quality evidence.

Indeed, studies and reviews since that time have re-examined the relationships between healthy eating and breast cancer. (13) It seems there is a clear link with obesity and post-menopausal breast cancer but this link may relate more to a lack of physical activity than unhealthy patterns of eating. However no one will exclude the possibility that having a healthy diet (and eating fruits and vegetables for example) may actually reduce breast cancer (14), although the evidence about early patterning has also become suspect and the data is considered inadequate.

A second, revised report by the AICR and the World Cancer Research Fund is expected to be published sometime in 2007.

International studies: In a study recently published in the Lancet (2005), in a comparative assessment for risks for cancers worldwide, authors found that risks for breast cancer attributable to lifestyle factors included obesity and lack of physical activity, along with alcohol use. They also found that risk factors differed in importance according to the level of

wealth in a country. In high-income countries, alcohol and obesity were reported as more common risk factors and in low-middle-income countries, physical activity is rated as a more common risk factor than alcohol or obesity. (15)

Cancer Research UK reports that, "The majority of studies on physical activity and breast cancer have found that being active reduces breast cancer risk by 30-40%. And the greatest benefits are seen in women who also have a healthy bodyweight. Physical activity protects against breast cancer in women both before and after their menopause. But scientists have seen the greatest risk reductions in women who are active early on in life before menopause. "Physical activity probably reduces breast cancer risk by lowering levels of insulin, hormones and growth factors. There is some evidence that physical activity can alter oestrogen metabolism to produce weaker versions of this hormone." (16)

What is known for sure is that many young women in Canada are less active in adolescence (17) It is reported that, girls become less active (than boys) as they grow. Among ages 5-12, 56% of girls are not active enough. High school is where physical activity really drops. Also, on its website, Statistics Canada reports data from the Community Health Survey in 2000/2001 that indicates "10% of Canadian girls ages 12-19 (were) described as overweight, while 3 % (were) described as obese."(18)

Limitations with the research:

Besides the limitations in establishing clear links with breast cancer, what is not known is whether these patterns (of unhealthy eating, being overweight or obese and lack of physical activity) in adolescence impact risks for breast cancer either pre or post-menopausally.

Clustering of Risk Factors for Chronic Disease

Recent research does provide good data for identifying young women as a target group, since it appears that risk factors to do with lifestyle often cluster in this age and gender group.

Canadian studies: In the OSDUS 2005 Mental Health and Well-being Report, it was noted that females are more likely to report being in fair or poor health, and that of the 18% of students who were not physically active at all in the previous 7 days, females were more likely to be inactive compared with males (20% vs16%) and this number has increased since 1997. (19)

One-fifth of students feel they are too fat and 1/10 say they are too thin. 29% are trying to lose weight. Females are significantly more likely to believe they are too fat, compared to males (25% vs14%).

International studies: In Australia in 2003, researchers found that "The emerging pattern in young Australian women is one in which health-risk behaviours are clustered, and often co-exist alongside emotional and mental health problems. The prevalence is increasing and the age at which they are adopting the behaviours is falling. Behaviours such as smoking, binge-drinking and unhealthy eating are associated." (20)

1.4 Partnerships and capacity-building

Parent Action on Drugs was able to draw from the members of the Ontario Health Promotion Resource System (OHPRS) to support this project. Funding received from the OHPRS French Language Services Committee provided additional support for translation of the survey and outreach materials. As well, colleagues within the substance abuse prevention field came on board, and finally young women of the target age joined the project team. Some of these had worked with PAD on previous projects and plus there were others who indicated an interest because of personal involvement with a close relative with breast cancer.

PAD also ensured there was a Francophone presence on the partnership, and at the recommendation of the funders, engaged representation from the Canadian Breast Cancer Network, a survivor directed national network of organizations and individuals.

The partnership in the end had representatives from each of the target risk factors, from the target age group, from both English and French-speaking communities and representatives from the community of breast-cancer survivors.

1.4.1 The Importance of the Project to Parent Action on Drugs

While the relationship between heavy drinking and breast cancer risks has been identified in the context of existing PAD resources and programs, and female-specific information has been included as well, the proposed project offered an opportunity to work closely with new partners, explore an issue in much more depth with the target population, and focus on a key risk issues for heavy alcohol consumption in conjunction with other lifestyle risks through a stepped approach, beginning with a thorough assessment and progressing through the assessment results to a planned health promotion initiative.

This project furthered PAD's work in three areas:

- it furthered partnership with organizations concerned with similar mandated issues, i.e., lifestyle impact on chronic disease prevention,
- it built on the concern with heavy drinking consequences and female specific vulnerabilities
- it supported PAD's mandate to build capacity among communities to build awareness and options for healthy behavioural choices for youth

1.4.2 The Importance of the Project to the Partners

The partners were clear that this had been a successful project and valuable to them in their respective work and personal lives. Some comments included:

- The model of the cross-sector partnership could be a model for other groups attempting similar work
- Although resources for development of the data tool was limited, the final product met standards of survey development, and those on the partnership who work with analysis of data noted that the instrument was a valid and credible tool
- Although resources for organizational development was limited, partners were very pleased with the level of organization
- Literature reviewed for the project was helpful particularly to health professionals across the sectors because each specialty area was learning about the others as we

the project was developed. It was voiced thusly by one partner, “It opened a world I’m not used to”.

- Local communities were very pleased about the opportunity to engage in such a project. Particular comments came from the French-speaking community where partners there are eagerly awaiting this report.
- The results of the online surveys identified specific areas of risk that to some extent had been replicated in previous studies. This study, however, clustered them and those partners who work specifically with young women found this very helpful.
- Partners also commented on how good it was to hear “what the young women were actually thinking” in the focus groups – and then to see this replicated in responses to the survey, including responses to open-ended questions.
- For one partner in a Francophone community, the project forged new links with the community college and increased her agency’s credibility for future work.
- All professional partners wish to continue with the project. At the writing of this report, it is not clear whether or not the young women involved will be able to continue based on their schedule differences this year.

1.4.3. The Importance of Having an Oversight Committee (according to the mandate of the CBCF – Ontario Chapter)

An Oversight Committee was established to:

- assess and review objectives and deliverables
- provide expertise on project management
- monitor for appropriate use of funds
- monitor for equitable access across Ontario.

The Oversight Committee vetted the terms of reference for the team partnership, the workplan, the survey, and the budget items.

One of the partnerships’ early challenges was whether or not to work within a formal framework with schools boards to conduct the focus groups and disseminate the survey. In the first iteration of the focus group development (in the English-speaking community), the process was avoided as the timing would have been detrimental to the progress of the project. In the second iteration, (in the French-speaking community), the process occurred with the school board involvement. In the process of dissemination, other venues (health promotion centers, public health centers, community health centers etc.) and other methods of online dissemination (listservs, youth-to-youth messaging) were accessed.

All processes worked well, but the problem-solving approach to deal with this challenge was supported by the Oversight Committee who identified realistic, and yet still scientifically-sound and ethical approaches to reaching young women about this issue.

1.5 Method

The Partnership developed the survey tool in a series of activities involving the partners and the target age group.

The partnership also included young women in the ages of 16-20, two of whom whose mothers’ had recently experienced breast cancer, and two who did not. These young women helped the other partners address the reality of their life, their challenges, their risks

and how to extrapolate this information to a population of other young women, with or without the additional risk factor of having a close relative with breast cancer

Their input helped to develop the focus group questions and format. Focus groups were held in October and November 2005 in the Niagara region with both high school students, and with University students with a total of 18 youth involved.

These questions were then taken by the French partners to be developed appropriately for a French-speaking audience. Then focus groups were held in February in Sudbury with students from secondary school and from a community college with a total of twenty youth.

One of the aims of the focus group format was to interest young women in joining the partnership. While this did not occur on an on-going basis, several women told us they were interested in the results and the next stages of development.

The final survey tool was developed in both languages after a process of analysis of the focus group answers and what appeared to be common expressions and ways of reacting to questions, as well as new questions themselves. The addition of many open-ended questions offered the opportunity for young women to give us their ideas and opinions beyond simply completing the tool. Several took this opportunity and the results offer key insights into their attitudes about risk factors and how these attitudes impact on their lifestyle choices.

Dissemination of the tool began at the end of April, 2006. The final survey tool was promoted and disseminated in two ways. The electronic version was promoted through each of the partners' listservs along with all their related health promotion networks. Also, youth networks were accessed via groups involved with Parent Action on Drugs in the past.

As well, paper copies were made available to high schools, sexual health centers and community youth and health centers across the province. It had been the partners' initial aim to reach 1000 young women with the tool. The actual extent of the outreach can only be approximated because so much of the dissemination was done online.

The final valid responses numbered 355 with 41 of those coming from French-speaking young women.

The data service used to collate the information was SurveyMonkey. This was an effective way to see the information change from entry to entry.

1.6 Limitations

Although there were limitations on resources and time, responses to the online survey tool were substantial, but fewer than expected. Also, by the time the survey was ready to go out, the university and community college year was over. While the team still accessed many young women of this age, we probably would have accessed many more if the survey had gone to them prior to the end of their school year. This is important when we look at planning next steps and ensuring a link with post-secondary students' timetables.

The decision about not going through the secondary school system process was also related to time-restrictions. As it turned out, because the survey tool was an online

instrument, we were able to access a youth-to-youth promotion with each sending the link on to their friends and colleagues.

The length of the survey was a deterrent to some respondents completing the questions. Because we were looking at three separate lifestyle factors, questions had to be asked about each. In testing the tool, it was found that the survey took approximately twelve minutes to complete, for someone with a good reading level. For those with more difficulty reading or a shorter attention span or less commitment to the project, the length and complexity of the survey could be a barrier.

There were also limitations on the information that is available to support specific behaviours as linking to breast cancer. While the literature supports a relationship, it is unclear whether or not breast cancer can be prevented by adhering to a healthy lifestyle, or whether or not specific issues (like obesity) contribute to pre or post-menopausal breast cancer, or whether certain pattern of behaviours (like heavy episodic drinking in adolescence) contribute to breast cancers down the line, or in fact if any of these patterns of behaviour are only linked to breast cancer if one has a close relative with breast cancer.

More research is needed into the specific links. Many of the young women reported that they would like to have the scientific basis for these risk factors. However, avoidance of a “victim-blaming” attitude must be avoided in the research as well as in health promotion/prevention initiatives. The young women involved in our research were clear that the questions asked must not judge their current lifestyle choices.

Finally, there were limitations on the number of French surveys completed online. Pains were taken to ensure that the development of the French survey tool followed the same process as the development of the English tool and was not just a direct translation. However, it was felt by the Francophone partners that many young women in French communities may well have chosen to answer the online survey in English. It is still so rare to have culturally and linguistically appropriate resources available to them, that many Francophone Ontarians automatically select the English version of things when presented with what is seen as only a direct translation. Having young women from francophone learning institutions participate equally in the focus group process did ensure that we received their input fully. The use of this kind of direct approach in order to engage members of the francophone community is recommended for future action.

2. Key Findings from the Survey

In total, 355 qualified women (i.e. in the 16-20 year old age category) began the survey; of these, 41 (or 8.6%) used the French language survey. 263 completed the survey – a completion rate of almost 75%.

The following key findings are from the English survey respondents, with French survey respondent information presented if substantially different.

2.1 Demographics

The respondents were fairly evenly distributed across the age range with the largest group in the 16 year old age category, representing 22% of the respondents. Almost a third were in grade 12; the 28% who were in college or university indicated a wide range of course of studies, although there was a somewhat heavier concentration in the area of sciences such as biology, nutrition and nursing. A small number indicated they were not in school and/or were working.

All parts of the province were represented by the respondents, with the largest single location being Toronto (n=65) and the region most represented being South West (n=68). The French language respondents were most heavily represented from North Bay and Sudbury.

29% of the respondents reported having a close relative with breast cancer; the answers of this sub-population will be noted where their answers are different from the whole. One respondent referred to the fact that she had received treatment for an unspecified cancer in the past year.

2.2 Lifestyle Practices and Attitudes

2.2.1 Alcohol Consumption

Almost half the respondents reported drinking at a rate of at least once a month, and two-thirds reported consuming 3 or more drinks at one setting; 16.4% did not drink at all. Most prefer mixed drinks, cocktails and coolers. The group with a close relative with breast cancer reported a slightly higher rate/pattern of alcohol consumption, and those completing the French language survey reporting a slightly lower rate/pattern of drinking.

The large majority of respondents (81%) answered that they saw “heavy drinking” (i.e., five or more drinks on one occasion) as a pattern with women in their age group, but most (74%) felt their own drinking pattern did not fit that definition. In fact, 39% of respondents (including drinkers and non-drinkers) said they were likely to continue the same drinking pattern in five years or even drink more (10%); almost a third felt they were likely to drink less. The majority (71%) did not feel that having information about the association of intensity of drinking with increased risk for breast cancer would affect their drinking patterns (50% said they were “not sure”).

When questioned about the reasons behind their answers to this question, the reason that was most applicable was “Everything causes cancer anyway” (60%). Twenty respondents expressed the opinion that their current level of drinking and/or non-drinking, meant that they would not need to change their current pattern.

"I hardly drink, if at all, so I'm not worried."

"I think I'm in the safe range and I know I will not ban alcohol from my life."

"I do not frequently go out on drinking binges – when I do decide to 'party' I make the most of it."

They also indicated the "it is more fun to drink than worry about it"; as one respondent remarked:

"I'm young and want to have fun, to an extent. I don't want to have to worry about cancer at 16."

2.2.2 Physical Activity

Over half (58%) of the respondents walk to school, and 44% reported that they participate in sports. They participate in these physical activities more than once a week, with 45% reporting daily or almost daily participation. Those answering the French language survey reported a lesser degree of physical activity, with 33% walking to school, 36% participating in sports and only 25% engaging in physical activity daily.

A large majority (79%) saw reduced physical activity as a pattern with women in their age group and two thirds said they were not as physically active as they thought they should be (86% of those responding to the French language survey). In both groups, more than a third anticipated they would be more physically active in five years from now although a slight majority (39%) felt they would remain the same.

2.2.3 Nutrition

Although 58% of respondents report eating in a health manner (i.e., a variety of foods from each of the 4 food groups), 30% say their eating patterns do not usually follow Canada's Food Guide recommendations.

Again, a large majority (85.7%) saw that poorer nutrition habits (i.e., a diet that is not low in fat, high in vegetables and fruit, with moderate portion sizes) were a pattern among women in their age group, although they were about evenly split as to whether they themselves fit this pattern. Slightly over half felt they were likely to eat in a healthier way in five years, with 27.5% saying they were likely to stay the same.

When asked about strategies for helping them become more physically active or following a more healthy pattern of eating, respondents suggested that activities that fit into their busy lifestyles, that they could do with friends, and having more affordable and available healthy nutritional options would be helpful to them.

2.3 Links between lifestyle factors and increased risks for breast cancer

A statement was made about the relationship between each of the lifestyle factors and the increased risk for breast cancer. Respondents were asked if they had heard about this relationship and how important it was for them at this stage of their lives (on a scale of 1 to 5, with one being “not at all important” and 5 being “very important”)

Alcohol consumption and the risk for breast cancer	Importance	Physical activity and the risk for breast cancer	Importance	Nutrition and healthy eating and the risk for breast cancer	Importance
84% had not heard of this link	81% rated this information as important to very important	68% had not heard of this relationship before	88.6% rated this information as important to very important	Only slightly more than half (51.4%) had not heard of this relationship	86% rated this information as important to very important

2.3.1. Reasons given to support their concerns

Respondents were asked to indicate how applicable a number of given reasons were in terms of how they rated these links between lifestyle factors and breast cancer risks – they were asked this question about each of the three risk factors.

Overall, most responded that they tried to be as healthy as they could – in all of the three categories; the information about the links between lifestyle factors and increased risk for breast cancer supported their attempts to be healthy by being physically active and eating as well as they felt they could. Almost two-thirds of respondents indicated that the information about the link between alcohol and increased risk for breast cancer was somewhat to very applicable to them “because I drink alcohol”.

“It is important to take this seriously”.

“You have to take care of your body now in order to be healthy in your future!”

When asked to rate whether having a relative who has or had breast cancer impacted on how important the information was for them, half (52%) said it was “not at all applicable”. The percentage answering this way remained the same whether the question was asked concerning alcohol consumption, physical activity or healthy eating. However, of the subset with a close relative with breast cancer, 86% - 91 % said that reason was quite or very applicable, again for all three lifestyle factors.

2.4 Raising awareness

Respondents were asked what would be the best way to raise awareness in other young women about the link between lifestyle issues and risks for breast cancer. The following chart indicates how the groups responded to a list of nine choices.

	All English survey respondents	English (close relative with breast cancer)	French survey respondents
1 st priority	From a breast cancer survivor	From a breast cancer survivor	In health and physical education curriculum
2 nd priority	From peers	From peers	From a breast cancer survivor
3 rd priority	From mothers	From mothers	From peers
4 th priority	In health and physical education curriculum	TV ads	From teachers
5 th priority	Messaging campaigns	In health and physical education curriculum	From mothers

It was important to check out with respondents whether answering questions about the potential links for the lifestyle factors with breast cancer made them anxious or nervous.

About half of the respondents on the English survey answered somewhat to very anxious (points 3/4 on a scale of 1 to 5); there was no difference among the subset of those who had a close relative who had breast cancer. Of the respondents on the French survey 35% responded in this way. Of all respondents, three respondents found that answering the questions made them extremely anxious.

When asked if there was anything that could lessen feelings of anxiety or nervousness about the subject, the respondents were fairly easy-going in their answers:

"I think it was fine, I'm simply an anxious person and am already higher at risk than the average person."

"Nah, it's just creepy to think about it."

"No, the questions didn't seem judgmental."

"Probably not, I know for my case there was just information I wasn't aware of so it's a little scary to learn about the links in our lifestyle and breast health."

It was also valuable to ask about the importance of specific information about risk factors, e.g., scientific research.

For the most part, respondents felt it would be important to have specific information: 31% indicated it would be important (point 3 on a scale of 1 to 5) and an additional 60% answering it would be very important (points 4/5 on the scale of 1 to 5).

2.4.1. Lifestyle choices and barriers to changing behaviour and raising awareness

The young women were asked what they saw as the barriers to trying to raise the awareness of young women about the relationship of each of the lifestyle factors and breast cancer (they could check all choices that they felt could apply, plus give additional answers). The following table shows the categories they felt applied most.

Barriers to trying to raise awareness of young women about the relationship between breast cancer and:

Alcohol use	%	Physical activity	%	Healthy eating	%
Young women in my age group don't think about the long term	79.7	There are too many messages concentrated on "getting skinny"	67.6	There is not enough time to eat in a healthy way – not a lot of healthy "fast food"	62.1
There are stronger influences (media, access, price promotion that support a social environment to drink	62	There is not enough time to build in physical activity to a busy schedule	63.5	There are too many messages already concentrated on weight loss	60.6
There are more important things to be concerned about, like school, my social life or my future	38	Physical activity messages are provided by women with "perfect" bodies	55.4	"Healthy" food is expensive	57.6
		Fitness clubs are seen as the only way to get active	55.4	"Healthy" food is difficult to prepare (or needs preparation)	56.1

The respondents were given the opportunity to expand on their answers to this question and many gave additional comments.

By far the most common response was in the category of "everything causes cancer anyway". In fact, many of the respondents wrote additional comments explaining their position:

"It's difficult to keep tabs on all the carcinogenics you ingest or subject yourself to on a daily basis...but there's only so far you can go. I really feel like it's getting ridiculous."

"We hear everyday on the news about how something new causes cancer. ...so I think people just give up on trying to stay cancer free."

In balancing the concern about breast cancer risks with their desire maintain their lifestyle – and particularly that part that involves drinking – the respondents felt that the links were not substantive enough, that possible negative consequences were too far off, and/or they were not willing to compromise their fun.

"Breast cancer is seen as something older women get and doesn't apply to young women, even though it is a direct result from the choices we make today."

"Everything is unhealthy and drinking every once in a while is fun."

"Breast cancer seems very far away in the future, so one night at a party is not going to impact it."

"Women my age don't listen to anything. We want to do our own thing"

A few respondents were particularly harsh critics of their peers:

"They feel they are exempt from risk";

"They do not think about it when they drink and many think it will never happen to them"

"Young women are stupid".

The lack of knowledge of the correlation and/or the lack of proven evidence also impacted their decisions: Comments such as *“I have never heard of this correlation”, “the facts are not proven enough by scientists”, and “there isn’t that much information out there”, “je voie pas le lien entre l’alcool et le cancer du sein”* point to this opinion.

Furthermore, their lives are busy and complicated: *“It all seems so serious, which it is, but it’s hard to worry about that plus school, friends, money and work. It’s too much to think about.”*

2.5 Receptivity to receiving information

The final question on the survey was: *If we were able to show you easy and fun ways to drink, eat and be active and which would reduce your risks for breast cancer, would you be interested in having this information?”*

Overwhelmingly, the young women responded “yes”; 92% of those responding to the English survey answered in this way (a lesser percentage – 78% - responded this way on the French language survey).

2.6 Summary and interpretation of results

Overall, we see a picture of young women who want to maintain a healthy lifestyle in terms of their eating and physical activity, but are reluctant to change their pattern of alcohol consumption. While their peers may be showing signs of “heavy drinking”, they themselves are having fun with alcohol and feel they show moderation overall, and do not anticipate that their patterns will change. The risk of cancer is something that is in the future, and any way, “everything causes cancer”. If they think about it, breast cancer is something that they can deal with, as they have seen role models (e.g., relatives who have had breast cancer) in their lives do. They will not commit to altering their current behaviour unless it is proven beyond doubt that there is concrete evidence that their current behaviour will contribute directly to a negative outcome. They show a reluctance to consider disease prevention in all areas – primarily, their concern about their eating, physical activity and drinking lifestyle patterns are with the immediate results for themselves in terms of body/ self image and social relationships. Yet they are almost unanimously interested in gaining information to help them make informed choices: *“This information aids in my decision to watch the amount of alcohol I consume”*. And they are incredibly “savvy” in their suggestions to pass along that information to other young women:

“Express the fact that lifestyle changes are easy and not to panic”

“Focus on how it can be prevented”

“Have more “maybe” options, instead of just yes/no”

“Just talk about the importance of healthy lifestyles”

“Let the young women ask questions they want to know”

“Start the education early, so that we can have a chance to make the right lifestyle choices from an early age”

“Offer programs and info packages specific to young women (i.e., actual examples of what we can do customized to our lifestyle)”

The results of this research show that while young women in this age range (16 – 20) show contradictory responses about their lifestyle choices and their concerns about breast cancer prevention. However, given their overall interest in health, they would be receptive to an

awareness initiative that appeals to their intelligence, ability to make choices in their own best interest, is non-judgmental of their current lifestyle choices and frames the messaging in terms of an early start to positive breast health practices.

3. Recommendations

Based on the Key Findings, the *Check It Out* Project Partners recommend the following:

- that the project results be used to seek additional funding to support a communications strategy for young women, ages 16-20, to raise their awareness about current evidence regarding lifestyle factors and risks with breast cancer and strategies for increasing breast health
- that a communication strategy address what the young women have told us about the barriers to receiving this information
- that a communication strategy use the tools and spokespeople that young women have identified as effective
- that the current partners stay involved throughout the development of this strategy, and that additional young women come on board to support the development, dissemination and evaluation of such a strategy

The Partners also recommend that the results of the survey and this report be made available to other health promoters who address the risk factors through websites, listservs and conferences.

The Partners recommend that other health promoters use the results of the survey and this report to identify other opportunities to work with young women around the clustering of these risk factors and potential issues for breast cancer specifically and healthy lifestyles in general.

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“Some of the main determinants of risk that are related to diet may have most effect in the first two decades of life. Rapid early growth and early menarche, and greater adult height increase risk of this cancer. Diets high in vegetables and fruits probably decrease the risk; high body mass probably increases the risk after menopause, and consumption of alcohol probably increase the risk. A family history of breast cancer increases risk.

The panel judges that plant-based diets, and the avoidance of alcohol, together with the maintenance of recommended body mass and regular physical activity, may decrease the incidence of breast cancer by about 33 - 50%. However, the panel also judges that these habits

will have most benefit if established before puberty and maintained throughout life. The potential for prevention starting in adult life may be limited to a 10 - 20% reduction conferred by maintenance of a recommended body weight and the avoidance of alcohol".

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