

Women In Touch™
Learning History

Organizations like ours try to learn from our experiences, especially the successful ones. This is a way of assessing our effectiveness and sharing information. It is an important process for the growth of any organization. In doing so, we have developed this Action Kit around the concept of a “learning history.” We went back to the source of our program - the people who initiated the idea, developed the program, formed the body, motivated the volunteers, implemented and managed the program, and represented the community. We tried to capture and convey the experience and understandings of these groups of people. The result of this new form of assessment, a learning history, is put forth in this Action Kit. We hope that what we have learned throughout this process will help you to develop a successful program in your community.

Within the pages of this kit we have gathered the building blocks for developing a program designed to mobilize people and generate a community support network. Obviously, the nature and success of the program has much to do with the people involved. It is therefore very likely that you will end up with some variation of this program specific to the personalities you bring to it. The building blocks described on the following pages are specific to *Women In Touch™*, a breast cancer awareness program developed by and for African-American women.

We hope that this Action Kit will help you lay the foundation. It is designed to give you the building blocks to get started. What you create will be up to the “architects, builders, carpenters, designers and occupants” who create and participate in your program.

Women In Touch™ staff members are more than happy to answer any questions you may have regarding this process. Please call Margaret McKinney-Arnold at (219) 284-6944 for more information.

Phil Newbold
Verfurth
CEO, Memorial Hospital/
Health System
Center

Bettye Green
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Marti
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The Problem

The fact is African-Americans are diagnosed with cancer and die from it more often than any other group.¹ The statistics are alarming!

∞ Breast cancer is the second leading cause of cancer death for African-American women.²

∞ For Caucasian women, breast cancer incidence rates increased from 83.9 per 100,000 women in 1973 to 116.7 per 100,000 women in 1987, then declined slightly to 112.7 in 1990. During the same period, the rate among African-American women increased from 68.8 to 95.8 per 100,000 women. Generally, the incidence of breast cancer is higher in Caucasian women than in African-American women only in the postmenopausal age (over age 45). Incidence rates are similar in African-Americans and Caucasians in the 40-44 year age group, and higher incidence rates are observed in African-American women in younger age groups (below age 40).³

∞ While the incidence of breast cancer in African-American women is lower than in white women, the death rate from breast cancer is disproportionately higher. Between 1973 and 1992, breast cancer in African-American women ages 50 and older increased more than 38 percent, and the death rate for this group increased 25 percent.⁴

∞ Women in lower socio-economic levels have a 10-15% lower survival rate from cancer than the average population. Thirty-four percent of African-American females have incomes below the poverty level.⁵

You may already know these facts. If so, that may be why you've requested this Action Kit. If not, the Kit can still help you move your community to action on this important public health concern.

Here in St. Joseph County, Indiana, where the *Women In Touch*TM (*WIT*) program was initiated, breast cancer incidence and mortality rates among African-American women were perceived to be higher than the national average. Marti Verfurth, Director of the Memorial Regional Cancer Center at Memorial Hospital in South Bend, Indiana, confirmed this fact after reviewing American Cancer Society (ACS) data and the Cancer Registry of Memorial Hospital of South Bend. The concern about the high incidence and mortality rates were the impetus for developing an African-American breast health awareness program, *Women In Touch*TM (*WIT*).

¹ "Spread the Word About Cancer: A Guide For Black Americans." NIH Publication No. 96-3412, National Institutes of Health, National Cancer Institute, November 1995, p. 1.

² Ibid., p. 3.

³ SEER Cancer Statistics Review: 1973-1990. U.S. Department of Health and Human Services, PHS, NIH, NIC. Bethesda, MD. NIH Publication No. 93-2789.

⁴ "African-American Women In TouchTM" Program Brochure. South Bend, IN.

⁵ Ibid.

The Plot

The Memorial Regional Cancer Center Director was instrumental in providing the foundation of information which later led to the development of a Minority Health Task Force and the *Women In Touch*TM program. Her concern about these alarming statistics motivated her to collect local data to support the facts. She attended conferences to learn more, and initiated dialogues with various African-American technicians, physicians, administrative staff and others throughout Memorial Hospital to develop a case for action.

In the fall of 1992, Ms. Verfurth began to brainstorm with African-American hospital personnel about this situation. They decided to form a Minority Health Task Force to develop an approach for breast cancer screening and education to reach the under-served African-American population.

After several meetings of the Minority Health Task Force they concluded that in order for a program to be effective and reach the African-American population they would need to directly involve the target group in planning, developing and implementing the program. This was indeed a critical decision. It was the impetus for creating a culturally sensitive program designed by and for African-American women.

In February 1993, the Minority Health Task Force invited approximately sixty (60) key female African-American community leaders to a dinner forum to discuss health issues and form an African-American Women's Advisory Panel. The attendees represented a wide range of African-American individuals; they included health care educators and other business professionals, ministers and church elders, housewives, cancer survivors and their loved ones. The Task Force purposely developed a loose format in order to create an open forum for discussion. Memorial Hospital leadership spoke about the disturbing African-American breast cancer incidence and mortality rates in the community. The hospital's CEO gave a verbal commitment to do whatever it took to create a program to address this issue. The *Women In Touch*TM program was born from this and subsequent meetings and has since taken on a life of its own.

The Purpose

The role and purpose of *Women In Touch*TM was defined during several organizational meetings. The African-American women who took up this effort were committed to seeing it grow and sustain itself. At this point breast cancer among African-American women was recognized as a community health problem and thus became a community initiative. Although Memorial Hospital was initiating the discussion, the effort was by no means owned solely by Memorial Hospital. The women who made up the organizational body of the program were representatives of many different types of professions and community-based organizations. They were also all volunteers. The interest in pushing forth with the development of an organized program was in the hands of those African-American community leaders and volunteers.

According to the American Cancer Society, if all women followed their guidelines for mammography and Breast Self Examination, the breast cancer survival rate would increase by 30%. With this in mind the goals for *Women In Touch*TM were set forth. In several meetings that followed that initial dinner forum, the purpose and mission for WIT were developed. Its mission, "to empower the African-American community to take a more active role in meeting their health needs," helped to clarify their purpose. That purpose is to do the following:

- Υο Raise awareness of breast cancer in the African-American community
- Υο Teach breast self examination
- Υο Assist in detecting breast cancer in its earliest stages
- Υο Increase the rate of participation of African-American women in mammography screening
- Υο Encourage participation in breast cancer prevention study through education and risk assessment
- Υο Educate the African-American community on pertinent high risk health issues

The African-American women volunteers who made up the organization developed goals for the program and, with the help of Memorial Hospital administrators and staff, created an organizational structure for *Women In Touch*TM. A Committee structure, generated by hospital staff, was formed as a result of a “natural” progression that started to form within the organization. The committee structure and functions look like this:

Committee	Function
Outreach	<ul style="list-style-type: none"> † Seek opportunities for exposure for WIT † Schedule presentations † Promote the WIT organization to the community † Monitor transportation needs † Distribute literature
Education	<ul style="list-style-type: none"> † Develop teaching guidelines † Purchase dark skin tone teaching models † Conduct WIT presentations † Teach Breast Self Examination † Assist in developing ethnically sensitive literature
Medical	<ul style="list-style-type: none"> † Lobby hospital for recruitment of African American physicians † Monitor access to and follow-up care † Develop physician education and understanding for the needs of African American women
Support	<ul style="list-style-type: none"> † Locate or provide dark skin tone prosthesis for WIT clients † Discuss potential effect of treatment on sexuality † Offer emotional support to women with breast cancer diagnosis † Recruit an African American breast cancer survivor in Reach to Recovery program † Encourage/support women with symptoms † Escort to physicians office when indicated
Resources	<ul style="list-style-type: none"> † Assist with developing and monitoring budget † Pursue community fund raising activities † Embark on marketing and advertising campaign † Approve expenditures of committees † Oversee expenditures of Annual Conference

Although the committee structure was in place, WIT volunteers were concentrating more on the operations of the organization than its structure. In August 1995, WIT volunteers were given office space at the hospital and began to operate more formally within the time-frame of the office hours. It wasn't until April 1996 that a Program Coordinator, Margaret McKinney-Arnold, RN, MS, was brought on board to solidify WIT operations and formalize the structure.

The Program

Women In Touch[™] (WIT) is described as a community-based organization of volunteers committed to raising awareness about breast cancer among African-American women. *Women In Touch*[™] provides breast cancer education and training, including breast self examination, and free screening and diagnostic mammograms to an under-served population of African-American women.

Women In Touch[™] achieves the goals set forth during the planning process by providing many services to our community. They have developed a program to identify and train African-American nurses and lay persons to teach breast self-examination, risk factors related to breast cancer, and the importance of mammography. Margaret McKinney-Arnold, WIT Program Coordinator confirmed that “since its beginning, more than 200 women have joined WIT and have provided 6,000 volunteer hours lending to the success and growth of *Women In Touch*[™]. These volunteers, some of whom are breast cancer survivors, are available to serve the WIT organization in whatever capacity needed.”

WIT volunteers are trained to use the American Cancer Society’s Triple Touch method of teaching Breast Self Examination (BSE). All of the WIT volunteers providing BSE training to the African-American community are themselves African-American. They use culturally sensitive materials, including brochures and other educational literature. The WIT staff also uses pigment appropriate (dark skin-toned) teaching aids and models in all of their training and educational sessions.

WIT volunteers and staff have also identified the target populations in need of breast health services including education, screening, treatment and systematic follow-up. They have developed several strategies for attracting attention to the program. They created a public service television commercial which airs on several local stations, a WIT informational brochure, and other promotional tools which are distributed at locations throughout the community. WIT volunteers even visit local grocery stores, at specific times, to hand out materials and register African-American women for services. Several other innovative and creative concepts have been developed and implemented in order to attract and identify those in need.

One of the main activities of WIT has been to identify and educate the medical community to the cultural concerns and fears of African-American women and men. Early in the process of developing *Women In Touch*[™], leaders recruited African-American physicians and nurses to help develop the program’s educational components. WIT coordinated with the Black Nurses Association to provide training in Breast Self Examination Triple Touch procedures. The medical community has been a critical element in the program’s success.

WIT volunteers and staff coordinated and hosted education seminars/workshops, attended many of the community health fairs, and conducted community presentations. Whenever there are community health fairs and forums, a trained WIT volunteer is sure to be there, handing out materials, signing women up for screening and answering questions. WIT also publishes a quarterly Newsletter, “Sisters.” This component has been instrumental in attracting participants and has secured WIT’s position as a committed, well respected organization within the community.

In October 1993, WIT representatives attended a national breast cancer conference in Washington, D.C. It was this conference that gave WIT leaders the idea to organize a local breast cancer conference in South Bend, Indiana. To date, WIT has organized and provided three

educational conferences. On April 23, 1994 WIT held its first conference entitled, "Taking Care of Self." Rev. Dr. Renita J. Weems, Assistant Professor, The Divinity School of Vanderbilt University was the keynote speaker and Ms. Jacquelyn L. Lendsey, Vice President for Corporate Communication & Community Development at the Greater Southeast Health System in Washington, D.C. was a visiting panelist on empowerment. The second annual conference held on April 22, 1995 was called "You Don't Have To Die." The keynote speakers were Ms. Zora Kramer Brown, Founder and Chairperson of the Cancer Awareness Program Services, Washington D.C. and Dr. Antoinette Yancey, MD, Ph.D., UCLA, Los Angeles, California. The most recent conference, "Moving Forward," was given on April 13, 1996. WIT invited keynote speaker, Byllye Avery, founding President of the National Black Women's Health Project. The objective for all three conferences was to provide an avenue for women of color to network and discuss critical health issues.

WIT also facilitates a support group which provides psychological, emotional and spiritual support to African-American women diagnosed with breast cancer. A new concept of "support partners" is currently being developed to match breast cancer survivors with those who are in the early stages of diagnosis and treatment. WIT also provides referral services to American Cancer Society *Reach to Recovery* and other services as needed. *Reach to Recovery* is a program designed to provide breast cancer survivors with support throughout the recovery process. Since WIT starting referring more and more African-American to *Reach to Recovery* there has been an increase in the number of African-American women participating in that program.

Critical to the survival of any non-profit organization is the identification of local donors and solicitation of contributions to finance breast health services. WIT has been able to secure several grants from sources outside the community to help fund specific elements of the program. The unrestricted support from Memorial Hospital has also been a key to getting the program off the ground and building a base of support.

The People

The success of any community program, and particularly this one, comes as a result of the people who have committed themselves to it. We stress the importance of making sure that all the "players" are present when developing, planning and implementing your program. In our case there have been four key role players in the *Women In Touch*TM program; they include the Volunteers, the Program Champion, the Community and the Hospital. The combination and coordination of each of these groups of people played a significant role in creating a successful program.

The WIT program has been championed by very strong and active African-American women leaders in our community, who volunteered their time and efforts. It's been their commitment to the issues of representation, awareness and advocacy that motivated them to form the WIT program. Their ability to attract other African-American women to the organization has been the cornerstone for developing a strong base of over 200 volunteers from which to carry out the *Women In Touch*TM program goals and objectives.

Bettye Green, a breast cancer survivor herself, and WIT Chairperson, has championed this program from early in its developmental stages. A key element to the success of this program has been her personal touch and commitment to addressing the issues of breast cancer among African-American women. With a nursing background to guide her, she began to ask questions and seek out information that would help guide WIT volunteers as they embarked on developing

the WIT program. She spent a great deal of time contacting other breast cancer programs and representatives throughout the country. The connections she made during this journey lead her into state and national level breast cancer organizations. Bettye now serves on the Indiana State Health Department Breast and Cervical Task Force; National Breast Cancer Coalition; and, is a member of two committees of the President's National Action Plan on Breast Cancer. She was also just recently appointed to the Department of Defense, US Army Medical Research and Material Command (USA MRMC), Breast Cancer Research Program, Integrational Panel, Programmatic Review Board.

The African-American community itself was also essential to the success of the WIT program. What happened after the initial meetings was described by all those involved as a "snow-ball" effect. The energy generated by the African-American community during the initial meetings not only empowered those involved but created a commitment to this effort that has since become the *Women In Touch*TM program. The St. Joseph County community also played a significant role in the success of the program. Several other health care providers and related organizations have coordinated with WIT to truly make this a community effort. WIT's success can be attributed to the fact that it is truly a "grassroots" organization. It has evolved from the leadership of several different community entities.

Memorial Hospital created the impetus for the program. Hospital staff recognized the issues and decided that something must be done. These individuals gathered the statistical data, performed a needs analysis and offered financial commitment to the program. They also provided structural and operational assistance to the WIT program without demanding ownership. In August of 1995, Memorial Hospital provided WIT volunteers with office space and supplies to further the process of development and, in April of 1996, hired a full-time paid Program Coordinator.

The Potholes

Carl Ellison, Vice President, Community Affairs at Memorial Hospital, an African-American community leader and WIT program advocate, believes that "the WIT program is not a 'recipe' type of program, it has evolved slowly through a process of forming, storming and norming."⁶ Throughout the "storming" stage of the *Women In Touch*TM program several issues came to the attention of program personnel and volunteers. Some of these issues were relative to the organizational structure and operations of the program itself. The remaining issues center around the target population and their access to and participation in the program.

The organizational issues that confronted the program leadership and WIT volunteers were, and some continue to be, resolvable. Some were perhaps even avoidable. From the start WIT volunteers were driven by their sense of ownership of the program, this is one of the major reasons for its success, it caused WIT leadership to go forward in what has been described previously as a "snow-ball" effect. The problems that later arose centered around "ownership" issues. Since there was no agreement between hospital leadership and leadership/volunteers as to the processes, procedures and roles each would be playing in the development of the *Women In Touch*TM program, there was no clear road map to follow. Looking back, both administrators and volunteers have agreed that this lack of formal structure caused some avoidable problems.

⁶ Rollin Glasser, E.D. Helping Your Organization Gear Up for Self Managing Teams. Organization Design and Development, Inc., 1991.

The “power struggle” that ensued as a result of unclear and undefined roles also revolved around some racial concerns. Since the WIT program was committed to serving the African-American population exclusively, in order to build trust and relationships in the African-American community, leaders believed that the program must be solely created by and for African-American women. This again is one of the strengths of the program and attributes to the overwhelming success, but within the organizational process it created chasms between white hospital administrators and African-American program leadership and volunteers.

WIT leaders and volunteers were also concerned about the hospital’s “agenda.” Could they trust that the hospital was an ally and would they provide all that was promised? Indeed the hospital had its own motives for initiating the first meetings, it was concerned about the alarming incidence and death rates among African-American women, but it also hoped to get African American women to participate in the Breast Cancer Prevention Trial (BCPT). The BCPT led the leadership to reveal fears of “being used” and brought up concerns about the WIT effort being for hospital gain. Both hospital administrators and program leaders agreed to eliminate the BCPT from the programmatic goals.

Other organizational issues centered around the fact that the WIT program was solely volunteer based. Many of the leaders pushed for paid staff positions early in the program’s development. This may have alleviated some of the “trust” issues and helped the hospital gain a strong partnership base early on. There were also some internal issues among the African-American women involved in the development of the *Women In Touch*TM program. During its formative stages, WIT volunteers were uncertain about the organization’s own internal make up. Some thought that the organization was made up solely of medical “professionals” and was limiting ownership. Others believed that the organization was to be “social” and should not be too formally structured. Through a long process of “storming”⁷ the WIT volunteers included African-American women with professional and non-professional backgrounds. The diversity of this group is another reason for its success and a credit to the organization.

The organizational issues that arose were not unresolvable and were, in fact, avoidable. The partnership that has developed through the “storming”⁸ stage, between hospital administrators and program leadership and volunteers, as a result of these concerns, is exemplary. We recommend that others forming similar programs develop clear and well defined roles for all involved from the onset.

As a guide to process development we have included a organizational chart in the back of this Action Kit. Many of the issues and concerns outlined here can be addressed if your organization follows the guidelines listed on the organizational chart. These are only suggestions that have surfaced as a result of the lessons we have learned throughout the “storming”⁹ process.

In addition to “organizational” issues we have been confronted with issues that center around the target population, those who receive services through the *Women In Touch*TM program. Fortunately, with a strong partnership and collaborative effort, WIT leaders and volunteers have

⁷ Ibid.

⁸ Ibid.

⁹ Ibid.

been successful at addressing these issues.

Some of the barriers and stigmas listed below have been described as “cultural” in nature. By no means do we assume that these are truths for all African-Americans. It has been our experience working with this specific target population of African-American women that enabled us to record these observations.

Many of the women who come through the WIT program do so as a result of the information and support they are given by WIT volunteers and staff. These women may also have other strong support systems (family, finances, education, etc.) that allow them to be able to do this. Unfortunately, not all African-American women have these support mechanisms. What WIT volunteers have found out about the ones who are reluctant to participate or just don’t, is that they almost always have barriers, stigmas and fears that make it difficult, if not impossible, for them to participate in the program.

The “stigma” of cancer for some African-American women can be great. Some women don’t even want to know if they have cancer. Many do not perform Breast Self Examinations (BSE) or obtain regular mammograms because they are afraid they will be diagnosed with breast cancer. They believe that if they get cancer they will die. According to Bettye Green, WIT Chairperson and breast cancer survivor, “There are many different myths associated with breast cancer. I’ve noticed that some women believe that they are being punished for something, that somehow they deserve this cancer. Sometimes these issues can center around a person’s religious beliefs.” This myth can cause women to keep quiet about their cancer experience. They don’t want their “business” in the street. Another common misperception is that cancer is something you can catch. Bettye and WIT staff and volunteers work hard to address the myths of breast cancer and to help alleviate women’s fears.

The fears of cancer, cancer treatment and the bigger issues of life and death, are always present. WIT staff continually deal with women who believe, according to Bettye Green, “that they are going to die.” They may think that therapy will be a waste of time, may cause a lot of pain and concerns of privacy and dignity which keep them from seeking medical assistance and treatment. There are also the obvious, and more talked about issues of sexuality and womanhood. Some women are scared to lose their breasts because somehow they will be losing their sense of “womanhood.”

Another issue specific to our community, is a lack of African-American physicians, medical personnel, and technicians. A way to alleviate fears and put people at ease is for them to feel comfortable with physicians and others who they encounter along the way; this includes the “gatekeepers,” those people who answer the phones, make appointments and forward personal and critical information to patients. WIT staff and volunteers help women through the various stages of screening, diagnosis, treatment and recovery by serving as support for the patient when dealing with these “gatekeepers.” A familiar face and a personal advocate makes this journey less scary.

In addition to the stigmas and fears, there are “barriers” that keep women from seeking assistance through WIT. Many women are not insured or under-insured; some do not even have a physician. Some have transportation, child care and other financial concerns that they consider more pressing to them than their own health. Margaret McKinney-Arnold, WIT Coordinator, has noticed that “some women just don’t have the time to come in for a mammogram, they have more immediate concerns, like work and family responsibilities. This can keep them from caring for their own personal health.” Margaret explained that

“African-American women have three weapons against breast cancer: monthly Breast Self Examination, annual clinical exams and mammograms.” The WIT Coordinator believes it is critical to the success of the program that women be encouraged to use these weapons.

There are some very personal issues surrounding breast cancer and African American women. Breast Self Examination (BSE) is one. Bettye Green mentioned that “some women believe that this is masturbation and were taught not to do this by parents and church leaders.” In order to help African-American women feel comfortable performing BSE, WIT uses educational tools and models that resemble African-American women.

In order for WIT leaders, staff and volunteers to move forward into the “norming”¹⁰ stage of development most, if not all, of these programmatic and cultural issues needed to be resolved or addressed in some way. It has been through the process of addressing these issues that the overwhelming success of the program became evident.

The Prize

Approximately, seven-hundred twenty (720) African-American women in the Michiana region have been screened for breast cancer through the *Women In Touch*TM program since March of 1994. WIT has held three annual conferences with national speakers. WIT has performed fifty (50) educational sessions and trained approximately two-hundred (200) volunteers. WIT staff members have tracked the number of women participating in all aspects of the WIT program.

Monthly reports are generated and distributed to funding sources. The success of this program cannot be judged solely on the “quantitative” outcomes listed above. The “qualitative” successes are more difficult to measure but we know that the WIT program has helped to save lives.

“I was first introduced to the Women In TouchTM program through the Reach to Recovery Support Group. I was initially attracted to the program because I was interested in talking with other African American women affected with breast cancer. I thought that they would have similar feelings, experiences and anxiety as me. As I got more involved in the program, I was comforted knowing that a group of African American women were there for me and always seemed willing to help. Women In TouchTM has been a great source of support for me. They help me learn more about financial responsibility and a clean living environment. This support enabled my family to live through a rough time, it has made our lives easier and taken away some of the regular burdens of life during a time of immense anxiety. I’d like for more women to know about this program. This support work of African American women has been of great importance to me and could benefit many others if they were introduced to it.”

- Melissa Grumbly

“Someone from Memorial Hospital contacted me to introduce me to the Women In TouchTM program. I was immediately interested in being involved in a united group of African American women. I learned a lot about breast cancer while supporting and being supported by other African American women dealing with breast cancer. Learning more about breast cancer has been a great source of support to me in dealing with my own disease and helping others understand the disease. I visited the White House to hear our own Betty Green speak with

¹⁰ Ibid.

Hillary Rodham Clinton. I was filled with joy and pride getting Black women at the table on the national level. I look forward to the continuation of this breast cancer support group to lend strength to African American women affected by this disease.”

- Barb Jones

Bettye Green, RN and WIT Chairperson believes that WIT has “brought about a change of life style for African-American women in St. Joseph County. *Women In Touch*[™] has helped to remove the stigma and cultural barriers associated with breast cancer by allowing African-American women to face the fear of cancer.” African-American women have accepted the WIT program; they trust program staff because they have been able to eliminate barriers to service and help them deal with their fears. African-American women have learned about the importance of good health care. They have begun to perform self breast exams, to visit their doctors more regularly, and to obtain mammograms as recommended. Unexpectedly, WIT’s influence expanded from the local community to both the state and national levels. As mentioned earlier, Bettye serves on many local, state and national level committees which focus on breast health. Her involvement with these organizations has brought the *Women In Touch*[™] program into the spotlight on several occasions. It is a testimonial to the importance of a program “champion.”

It is our belief that a successful breast health awareness program, specific to African-American women, can be developed when there is cooperation, collaborative planning and long-term commitment between health care institutions and energetic and committed leaders within the community. We hope that the information provided in this Action Kit will enable you to successfully structure and develop a *Women In Touch*[™] program in your community. Good luck!

NOTES