

# HEALTH DEPARTMENT DREAMIN': An Electronic Cancer Screening Follow-up System

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## EXECUTIVE SUMMARY

National 25-year trends in age-adjusted mortality rates, for breast and cervical cancer, show a decline in mortality largely due to more widespread and effective screening among women. The state of Kentucky is closely aligned with the nation in its recent age-adjusted mortality rate for breast cancer, but exceeds the national rate for cervical cancer mortality.

In 1990, Congress passed the National Breast and Cervical Cancer Early Detection Act, freeing federal funds to be administered through Centers for Disease Control and Prevention for state women's cancer screening programs. CDC continues to monitor screening compliance rates of these state programs. **Because of the demand this places on local health departments and their limited staff, Kentucky Women Cancer Screening Program has discovered non-compliance regarding follow-up for patients with cancer screenings.**

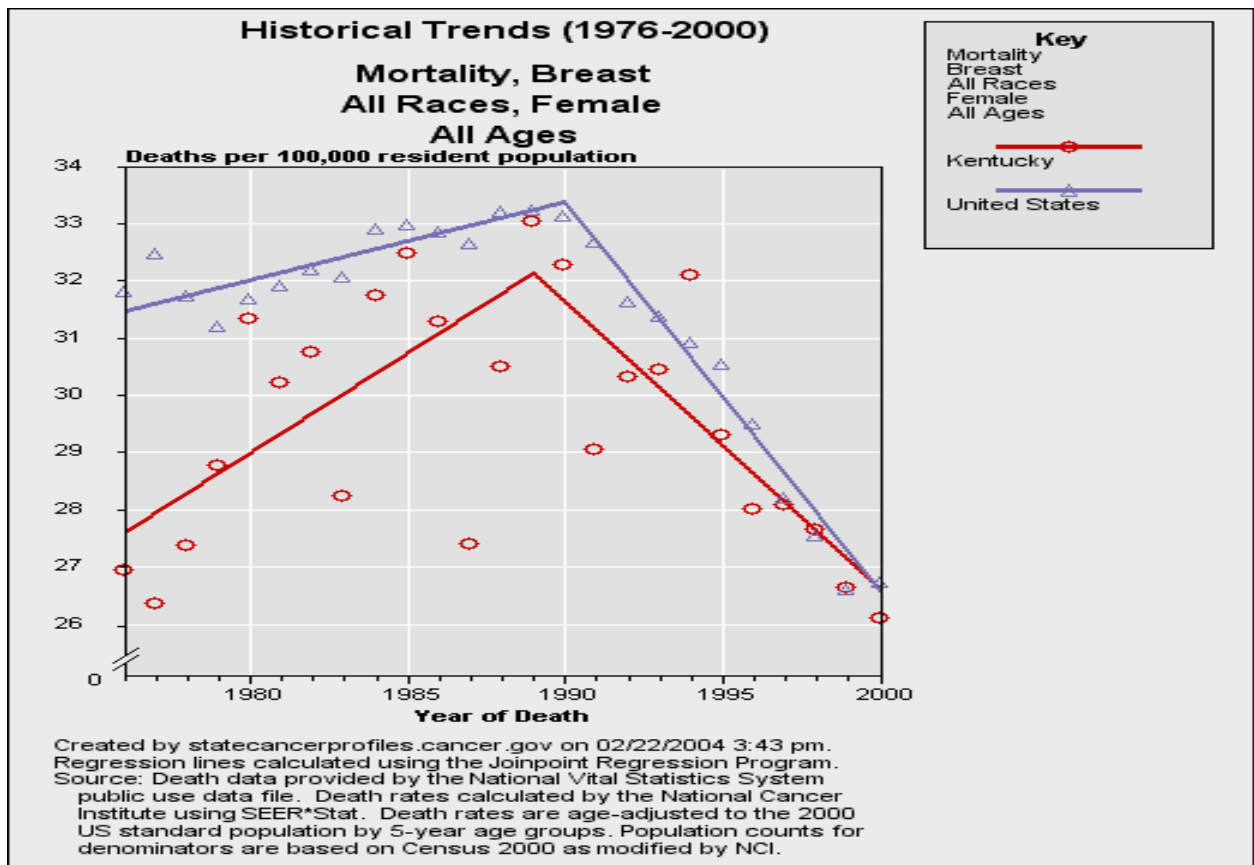
To assist local health departments with the burden of improving compliance rates, we have designed matrices for breast and cervical screening follow-up and developed an electronic system from the matrices which can replace labor-intensive tracking. The electronic system can generate reminder letters for normal, as well as abnormal reports. In addition, it can generate letters to notify women to schedule their annual mammograms and Pap tests (for home contacts only).

Our project is in Phase I of piloting the electronic system in two counties. We recommend formal testing to compare its effectiveness with standard manual tracking... Phase II. Should there be evidence showing greater effectiveness for the electronic system, we recommend marketing, in partnership with Custom Data Processing and KWCSP, across the commonwealth.... Phase III. Finally, national marketing, through CDC, may be possible... Phase IV.

## INTRODUCTION

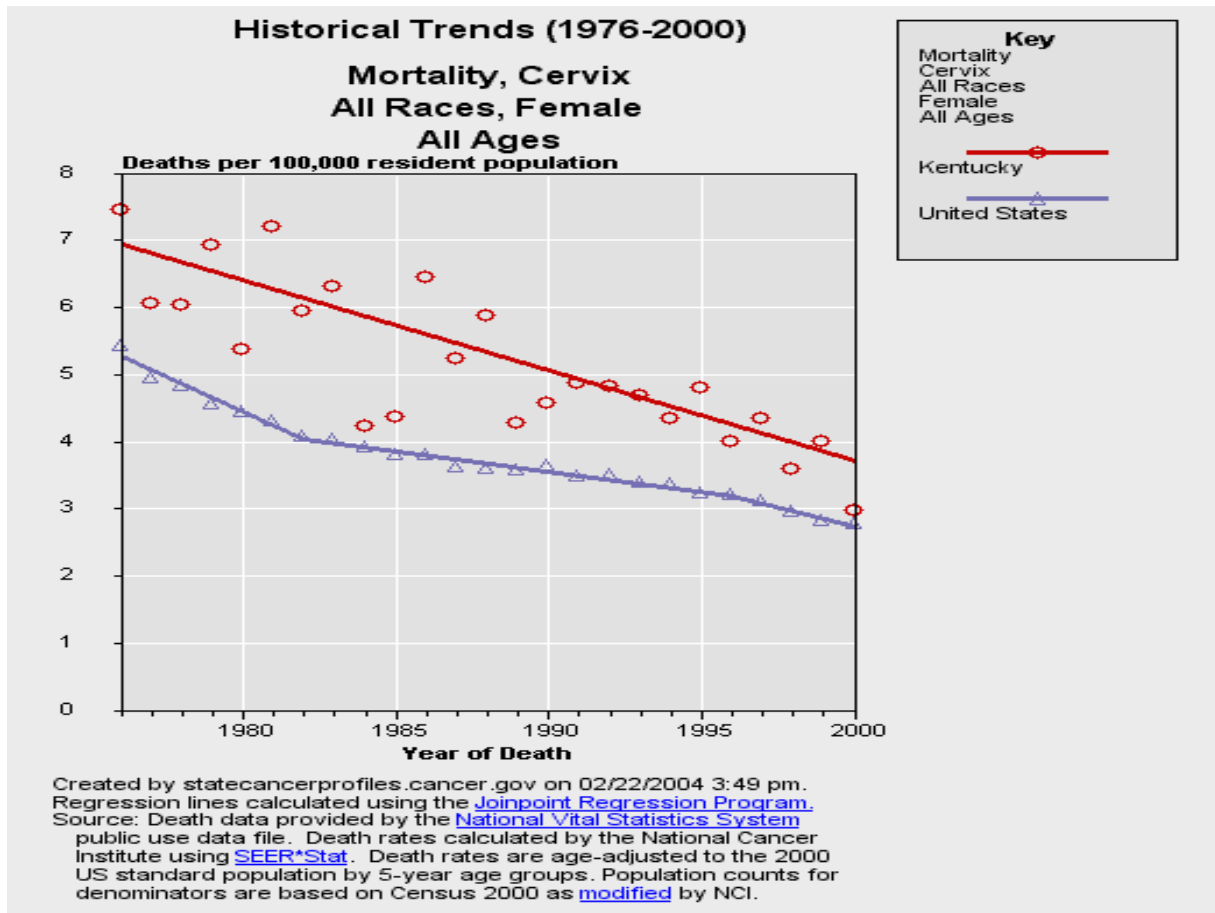
Cancer is the second leading cause of death among women across the Commonwealth of Kentucky as well as nationally. Breast cancer is the most common form, and the second leading cause, of cancer deaths among Kentucky women. The National Cancer Institute estimates that approximately 1 in 8 women, in the United States, will develop breast cancer during her lifetime. After the age of forty, a woman's risk for developing breast cancer rises with her age.

Data reported from the National Vital Statistics System shows a national decline in breast cancer mortality from approximately 31.5 per 100,000 of population in 1975, to a regressional average of approximately 26.8 in 2000. The highest rates of breast cancer mortality were experienced in the late 1980's with approximately 33.25 deaths per 100,000 women. Therefore, improvements in screening, early detection and treatment, have shown the greatest impact of breast cancer mortality decline occurring in the past ten years. Kentucky experienced its greatest mortality due to breast cancer in the late 1980's with approximately 31.75 deaths per 100,000. However, Kentucky experienced a tremendous decline in breast cancer mortality since 1990, and reached about the same rate of breast cancer mortality in 2000, as the nation, with approximately 26.8 deaths per 100,000. (See Graph below)



The mortality rates for cervical cancer have also been declining nationally. According to the National Vital Statistics System, cervical cancer mortality has decreased from (5.25)

Data reported from the National Vital Statistics System shows a national decline in cervical cancer mortality from approximately 5.25 per 100,000 of the female population in 1975 to approximately 2.8 in 2000. Although Kentucky shows approximately the same rate of decline, the state still has a higher age-adjusted mortality rate for cervical cancer than the nation with a regressional average of approximately 3.75 cervical cancer deaths per 100,000 of population. (See Graph below)



Health Departments have a unique opportunity to educate women on the benefits of early detection of breast and cervical cancer. Early detection of breast and cervical cancer with a corresponding decrease in mortality is dependent on periodic screening. In 1990, Congress passed the National Breast & Cervical Cancer Early Detection Act to provide funding to states through the Centers for Disease Control and Prevention. Since that time, breast cancer screenings in Kentucky local health departments have increased 17-fold (Kentucky Women’s Health 2002). Local health departments provide services

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through the Kentucky Women’s Cancer Screening Program (KWCSPP), including female adult preventive visits, cancer screening, diagnostic evaluation, patient education, and case management. Providers are expected to adhere to the written protocols as found in the Public Health Practice Reference Manual. These protocols are based on grant requirements and the recommendations of the Medical Advisory and Breast Cancer Advisory Committees.

Abnormal screening results from mammograms and pap smears are assigned to a Nurse Case Manager for tracking and follow-up. This involves the Nurse Case Manager to contact the patient, discuss the results and educate the patient in regard to the follow-up needed. Because diagnosis is to be made within 60 days, it is imperative that the Nurse Case Manager be effective in his or her duties. Nurse Case Managers currently use a manual tracking system for abnormal cancer screening follow-up. There is no uniform tracking system across the state to assist Nurse Case Managers in what can be an overwhelming job. One disadvantage of using a manual tracking system is the time that it involves for the Nurse Case Manager. Depending on the number of screenings done, the nurse may quickly find herself buried under charts of clients needing tracking and follow-up services. It can be very time consuming. In order to comply with standards, the nurse is often pulled from clinic services to complete follow-up. With a manual system, there is also increased risk for human error.

## PROBLEM STATEMENT

Due to the aforementioned mortality rates of breast and cervical cancer within the state of Kentucky, there has been a greater focus placed on preventive cancer screenings within the local communities. **Because of the demand this places upon local health departments and their limited staff, the Kentucky Women’s Cancer Screening Program (KWCSPP) has discovered non-compliance regarding follow-up for patients with cancer screenings.** According to statistics provided by the KWCSPP, status of treatment for screenings performed prior to the diagnostic cutoff date with a final diagnosis of breast cancer (percentage with treatment started) showed Kentucky being well below the CDC target of >90% with a rating of 78.9%. Status of treatment for cervical screenings performed prior to the diagnostic cutoff date with a final diagnosis of CIN II or CIN III/CIS or invasive carcinoma (percentage with treatment started) showed Kentucky to be substantially below the CDC target of >90% with a rating of 48.7%. This may be partly due to Lack of a uniform tracking system. (See Causal Loop Diag.)

Increasing Breast/Cervical  
Cancer Burden



Non-compliance with follow-up guidelines

Unwillingness of patients to respond

## **PROJECT DESCRIPTION AND METHODS**

It is our goal to develop an electronic tracking system for cancer screening follow-up. We feel that having this system in place would increase efficiency, decrease chance of human error, increase patient compliance, and more importantly improve patient outcomes.

In order to meet our goal, several planning meetings were held to discuss the feasibility, resource requirements, and possible funding sources for the project. (See timeline below) Our project team could not complete this alone; it called for partnerships. Custom Data Processing (CDP) became a partner early in the planning process. Others involved in the planning process include KWCSF Staff, local health department nursing and finance staff, and Public Health Nurse Consultants. The feasibility of the project was confirmed by all parties involved.

More in-depth meetings occurred with CDP to look at current Kentucky Public Health Practice Reference protocols for Breast and Cervical Cancer Screening tracking. These protocols were used to develop matrices for CDP to utilize in writing the program needed to carry out this project. (See charts following this section) When pap or mammogram results are sent to the local health department, the Nurse Case Manager will assign the proper code to the result. This data is then entered into the system. Depending on this result, the appropriate letter for patient contact will be generated by the computer. The Nurse Case Manager will be able to personalize this letter before it is printed off. The system will track the abnormal results by providing reports depending on data entered. Funding for CDP to complete the programming was provided by KWSCP.

## **PROJECT TIMELINE**

- June 4,5, 2003: KPHLI Summit One. Orientation to change master project. Formulation of problem statement, objectives, timeline, and systems theory causal loop diagram for our project.
- June 16, 2003: Online chat meeting to discuss strategies for partnering with Kentucky Women's Cancer Screening Program (KWCSF) and Custom Data Processing (CDP) Company in Frankfort.
- July 17, 2003: Meeting with Margaret, KWCSF and CDP in Frankfort to discuss feasibility of our project. Encouragement from all sides.
- July 31, 2003: Meeting with our Margaret and KDPH staff to review current protocols and patient letters for notification of abnormal mammography and Pap test screening results. Discussion of funding for pilots in three counties.
- August 12, 2003: Meeting with Margaret and CDP in Frankfort to give project specifications, discuss budget and contract.
- September 9, 2003: Follow-up with CDP for progress review and suggestions.

- September 22,23,2003: KPHLI Summit Two. Identification and description of the correlation of our change master project with the Ten Essential Public Health Services. Further discussion of funding issues.
- November 13, 2003: Meeting in Frankfort with Margaret and CDP for system demonstration and review.
- December 2003: Progress review with Margaret in Frankfort. Notification of KWCSF funding for our pilots.
- January 1, 2004: Updated protocols from Public Health Practice Reference. Updated matrices and provided to CDP for programming correction.
- January 14, 2004: Met in Frankfort for initial planning of presentation.
- February 4,5, 2003: KPHLI Summit Three. Summarization of project status with plans for dissemination of results. Discussion of formal testing and marketing.
- February 16, 2003: Meeting in Monticello to continue planning project presentation and report.
- February 18, 2004: Pilot begins in Barren County.
- February 20, 2004: Pilot begins in Pulaski County.
- March 1, 2004: Meeting in Monticello writing project report and planning presentation.
- March 8, 2004: Meeting in Monticello completing project report.
- March 12, 2004: Meeting in Somerset to begin working on presentation.
- March 23, 2004: Meeting in Somerset to continue working on presentation.
- March 29, 2004: Meeting in Somerset to complete presentation.

The following Essential Public Health Services were involved in this project:

- #1 Monitor health status to identify community health problems.
- #2 Diagnose and investigate health problems and health hazards in the community.
- #3 Inform, educate, and empower people about health issues.
- #4 Mobilize community partnerships to identify and solve health problems.
- #5 Develop policies and plans that support individual and community health efforts.
- #7 Link people to needed personal health services and assure the provision of health care when otherwise unavailable.



**Kentucky Public Health Leadership Institute Change Master Project**

**"The Mammias & The Papa"**

**Electronic Cancer Screening Follow-up System Tracking Matrix - Breast**

		Notification				Objective			
Results Description	Results Code	Verbal Notification	Letter	Certified Letter	Home Visit	Referral - Surgeon	Repeat ASAP	Repeat - 6 month	Repeat - 12 month
Abnormal Clinical Breast Exam (CBE)		X				X			X
Assessment Incomplete	0	X	0	B - 0			X		X
Negative	1		1						X
Benign Finding	2		2						X
Probably Benign	3	X	3	B - 3				X	X
Suspicious Abnormality	4	X	4	B - 4	X	X			X
Highly Suggestive Malignancy	5	X	5	B - 5	X	X			X
Unsatisfactory	6	X	6	B - 6					X
<p>Verbal Notification must be accomplished within 10 working days after the abnormal report is received. If verbal notification is not made on the first attempt, send letter immediately.</p>									
<p>Letter must be sent and response from patient within 10 calendar days after results if no verbal notification. If no response, send Certified Letter.</p>									
<p>Certified Letter must be sent and response from patient within 10 calendar days after the Letter Expiration. If no response, per matrix, finalize process or do Home Visit.</p>									
<p>Home Visit as required per matrix to be done 10 calendar days after the Certified Letter Expiration. If no contact, finalize process.</p>									
<p>Referral - Surgeon must be done with a final diagnosis within 60 days after the abnormal screening test.</p>									
<p>Repeat - As soon as possible - Appointment needs to be made and system generate a reminder letter for the appointment one week prior. If no appt., system generates letter to schedule appt. immediately.</p>									
<p>Repeat - 6 month - Appointment needs to be made and system generate a reminder letter for the appointment at 5 1/2 months. If no appt., system generates letter to schedule appt. at 4 months.</p>									
<p>Repeat - 12 month - Appointment needs to be made and system generate a reminder letter for the appointment at 11 1/2 months. If no appt., system generates letter to schedule appt. at 10 months.</p>									

**Kentucky Public Health Leadership Institute Change Master Project  
"The Mamas & The Pappa"  
Electronic Cancer Screening Follow-up System Tracking Matrix - Cervical**

Results Description	Results Code	Notification				Objective							
		Verbal Notification	Letter	Certified Letter	Home Visit	Referral - Colposcopy	Referral - Colpo w/Endocervical Curettage	Referral - Colpo w/ Endometrial Biopsy	Pregnancy Verification	Referral - Physician	Repeat - 3 month	Repeat - 6 month	Repeat - 12 month
Normal	1		1										X
Normal w/ Yeast	1		1a										X
Normal w/ Inflammation	1		1b										X
Atypia (ASCUS)	2	X	2	C - 2								X	X
Atypia (ASCUS) Repeat	2	X	2a	C - 2a		X							X
Atypia (ASC-H)	3	X	3	C - 3		X							X
Low Grade Intraepithelial	4	X	4	C - 4		X						X	X
LGI - 19 yr old or less w/o 3 risk factors	4a	X	4a	C - 4a								X	X
High Grade Intraepithelial Neoplasia	5	X	5	C - 5	X	X							X
Squamous Cell Carcinoma	6	X	6	C - 6	X					X			X
Adenocarcinoma or Adenocarcinoma-in-situ	7	X	7	C - 7	X					X			X
Unsatisfactory	8	X	8	C - 8							X		X
Atypical Glandular Cells (AGUS)	9								X				
If Pregnancy Verification is Positive Stop	9									X			
If Pregnancy Verification is Negative	9	X	9	C - 9	X		X						X
If age 35 & older	9	X	9	C - 9	X		X	X					X
If Atypical Endometrial Cells	9	X	9	C - 9	X			X		X			X
If Atypical Endocervical Cells	9	X	9	C - 9	X					X			X
Verbal Notification must be accomplished within 10 working days after the abnormal report is received. If verbal notification is not made on first attempt, send letter immediately.													
Letter must be sent and response from patient within 10 calendar days after the Verbal Notification attempt. If no response, send Certified Letter.													
Certified Letter must be sent and response from patient within 10 calendar days after the Letter Expiration. If no response, per matrix, finalize process or do Home Visit.													
Home Visit as required per matrix to be done 10 calendar days after the Certified Letter Expiration. If no contact, finalize process.													
Referral - Colposcopy must be done with a final diagnosis within 60 days after date of screening.													
Referral - Colposcopy w/ Endocervical Curettage must be done with a final diagnosis within 60 days after date of screening.													
Referral - Colposcopy w/ Endometrial Biopsy must be done with a final diagnosis within 60 days after date of screening.													
Pregnancy Verification must be done before any other objective can begin on Results Code 9.													
Referral - Physician													
Repeat - 3 month - Appointment needs to be made and system generate a reminder letter for the appointment at 2 1/2 months. If no appt., system generates letter to schedule appt. at 2 months.													
Repeat - 6 month - Appointment needs to be made and system generate a reminder letter for the appointment at 5 1/2 months. If no appt., system generates letter to schedule appt. at 4 months.													
Repeat - 12 month - Appointment needs to be made and system generate a reminder letter for the appointment at 11 1/2 months. If no appt., system generates letter to schedule appt. at 10 months.													

## **RESULTS**

The initial, anticipated outcome of our project has been to design and implement a fully functional, effective and efficient electronic cancer screening follow-up reporting system to be installed within at least three local health departments. The overall goal of the project has been to assist local health departments to meet compliance standards according to Centers for Disease Control and Prevention (CDC) and the Kentucky Women's Cancer Screening Program (KWCSPP).

To date, the system design is complete and has been in the pilot phase a little more than a month in both Pulaski and Barren Counties. Previous to the pilot site implementation, there were a few changes made to the Public Health Practice Reference protocols for the cancer screening follow-up. These changes were communicated to CDP through updated matrices to reflect the revisions for which they were able to make immediate system programming changes. This supports the ability of CDP to efficiently administer future changes in the electronic system. Initial comments from local health department case managers have been positive. They have been appreciative of our attempt to make their jobs easier, more efficient and compliant with CDC and KWCSPP standards.

We had hoped to have the system fully functioning, tested and presented to the Kentucky Health Department Association (KHDA) before this date. However, we plan on continuing to work on this project in partnership with CDP and KWCSPP by presenting the system to the KHDA so that all health departments within the state may have the opportunity to benefit from it.

## **CONCLUSION**

In summary, the electronic cancer screening follow-up system has the ability to affect many lives and organizations in not only Kentucky, but many other states in the U.S., through the outsourcing of Custom Data Processing's electronic systems. Patient lives may be saved through early detection and timely follow through. Cancer screening case managers may experience a much greater degree of job satisfaction due to this system allowing them to keep up with follow-up in a timely manner. Organizations may benefit through increased productivity by changing manual processes into electronic ones.

We have confidence (but not yet evidence) that our electronic cancer screening follow-up reporting system may enhance the cancer screening follow-up process for local health departments choosing to adopt it. We owe much thanks to our partners who helped make this project possible, the Department of Public Health's Kentucky Women's Cancer Screening Program staff and the staff of Custom Data Processing. This project has demonstrated the dedication and commitment of everyone involved. We have experienced satisfaction in watching leaders from many programs, with different agendas, partner for mutual benefit and success.

We hope that future KPHLI scholars will consider expanding the pilot phase of our project and formally testing our system in comparison to manual tracking. If testing reveals evidence that our system is more effective than manual tracking, a third KPHLI Change Master Project group could use the evidence to plan and implement marketing across the state. Future scholars might also consider promoting our system to health departments in other states, with initial emphasis on departments who are outsourcing their computer services through Custom Data Processing.

## **LEADERSHIP DEVELOPMENT OPPORTUNITIES**

### ***Sheila Atwell***

I am thankful to have been a scholar of KPHLI 2003-04. What an honor it has been to meet and get to know so many other public health professionals. I have found support and encouragement in my new friends. I have learned much from the summits and am excited to put the knowledge gained into practice. Working with this change master group has been rewarding. No matter how small a group may be, when you have a unified goal, you can succeed! Thanks to all of you who assisted us with our project. Thanks to those who support KPHLI. I feel better equipped to become the leader I want to be.

### ***Randy Gooch***

The leadership institute has provided me with a wonderful opportunity to enhance my leadership abilities as well as learning useful leadership tools. The greatest benefit I have received is learning the characteristics of a true leader, one who may not have the individual ability to generate envisioned outcomes but one who has the ability to utilize the resources of others through motivation and encouragement to accomplish a shared vision. My weakness was one of thinking my way was always the best way. I believe the work we have done in our Change Master Project has offered me the opportunity to grow to that end in realizing different points of views affect different aspects of a particular solution therefore giving a much more well rounded approach to obtaining the goal. I am truly indebted to those who have made this experience possible. Thanks to my Director, the Department of Public Health, Cynthia, Terri, Tyeshia and the University of KY. Also, I am indebted and thankful to Catherann Key and Debby Bridges of the Kentucky Women's Cancer Screening Program and Gary Causey of Custom Data Processing for their commitment and contributions toward making this project a success.

### ***Sandy Good***

KPHLI has given me greater insight into my leadership skills and enabled me to formulate a long-range plan for personal development, which will continue to enrich my professional performance. I have enjoyed learning to know everyone involved this year. Summits have afforded me time to explore assessment, policy and assurance as they apply to real issues in health care across Kentucky and the nation. Engagement in our change master project, as a team member, has demonstrated for me what significant change small groups of dedicated public health professionals can accomplish for the good of the commonwealth.

## REFERENCES

Cabinet for Health Services, Department for Public Health, Kentucky Public Health Practice Reference, January 1, 2004

Cabinet for Health Services, Office of Women's Physical & Mental Health, Kentucky Women's Health 2002: Data, Developments and Decisions, May 2002

National Vital Statistics System, [www.statecancerprofiles.cancer.gov](http://www.statecancerprofiles.cancer.gov) , Historical Trends (1976-2000) Mortality, Breast All Races, Female All Ages, (Accessed 2/13/04)

National Vital Statistics System, [www.statecancerprofiles.cancer.gov](http://www.statecancerprofiles.cancer.gov) , Historical Trends (1976-2000) Mortality, Cervix All Races, Female All Ages, (Accessed 2/13/04)