Project SAFe

Promoting better healthcare for women

THE SCREENING ADHERENCE FOLLOW-UP (SAFe) PROGRAM:

Patient Navigation/Patient navigation/case management the SAFe Way

A TOOLKIT FOR EVIDENCE-BASED PATIENT NAVIGATION/PATIENT NAVIGATION/CASE MANAGEMENT TO IMPROVE ADHERENCE TO ABNORMAL CANCER SCREEN FOLLOW-UP

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Preface

A SAFe pilot replication and randomized study project was funded by a cooperative agreement awarded in October, 1997 to the Institute for the Advancement of Social Work Research (IASWR) by the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) of the Centers for Disease Control and Prevention (CDC) (www. cdc.gov/cancer/NBCCEDP) . A SAFe translational implementation demonstration project in high risk community based clinics selected via project request by the 5 clinics was funded in January 2000 to IASWR by the Cancer Detection Section of the California Department of Health Services in cooperation with CDC aims to advance patient navigation/patient navigation/case management demonstration projects in community clinics serving NBCCEDP program eligible patients.

An estimated 8–11% of U.S. women of screening age are eligible to receive NBCCEDP services. Federal guidelines establish an eligibility baseline to direct services to uninsured and underinsured women at or below 250% of federal poverty level; ages 18–64 for cervical screening; ages 40–64 for breast screening.

To improve women's access to screening for breast and cervical cancers, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which guided CDC in creating the NBCCEDP. The NBCCEDP provides screening support in all 50 states, the District of Columbia, 5 U.S. territories, and 12 American Indian/Alaska Native tribes or tribal organizations, and helps low-income, uninsured, and underinsured women gain access to breast and cervical cancer screening and diagnostic services. These services include

- Clinical breast examinations.

- Mammograms.

- Pap tests.

- Diagnostic testing for women whose screening outcome is abnormal.

- Surgical consultation.

- Referrals to treatment.

Since 1991, the NBCCEDP has served more than 3 million women, provided more than 7.2 million screening examinations, and diagnosed 30,963 breast cancers, 1,934 invasive cervical cancers, and 101,624 precursor cervical lesions, of which 43% were high-grade. In October 1998, Congress modified the legislative authority of the NBCCEDP to include patient navigation/patient navigation/case management as a program component in response to the demonstrated need for more intensive individualized intervention for high-risk women with special needs. In late 1999, CDC provided national guidelines for these patient navigation/case management services within NBCCEDP programs. SAFe patient navigation/case management is consistent with the CDC Patient navigation/case management Policy, as it addresses each element of the guidelines.

In fiscal year 2006, the NBCCEDP

- screened 380,719 women for breast cancer using mammography and found 4,013 breast cancers, serving 14.7% of all American women eligible to participate in the NBCCEDP for breast cancer

- screened 367,200 women for cervical cancer using the Pap test and found 5,162 high-grade and invasive cervical lesions, serving 6.7% of all American women eligible to participate in the NBCCEDP for cervical cancer

In 2000, Congress passed the Breast and Cervical Cancer Prevention and Treatment Act, which gives states the option to offer women in the NBCCEDP access to treatment through Medicaid. To date, all 50 states and the District of Columbia have approved this Medicaid option. In 2001, with passage of the Native American Breast and Cervical Cancer Treatment Technical Amendment Act, Congress explained that this option also applies to

American Indians/Alaska Natives who are eligible for health services provided by the Indian Health Service or by a tribal organization.
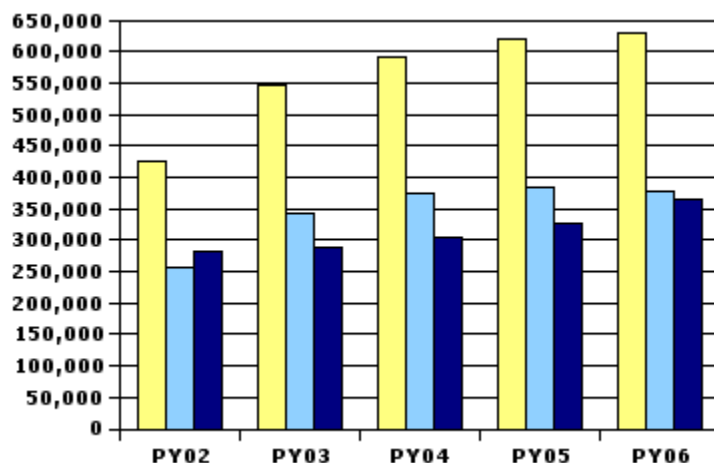
To reach underserved women, the NBCCEDP supports an array of strategies, including program management, screening and diagnostic services, data management, quality assurance and quality improvement, evaluation, partnerships, professional development, and recruitment. Providers in the program work collaboratively to provide breast and cervical cancer screening, diagnostic evaluation, and treatment referrals (where appropriate). The program's continued success depends in large part on the complementary efforts of a variety of national organizations, as well as on state and community partners.

In 2005, CDC released *The National Breast and Cervical Cancer Early Detection Program: 1991–2002 National Report,* (PDF-1.3MB) the first summary of the program's progress. The report provides information about the program's framework, history, and future direction, as well as data on breast and cervical cancer screening outcomes for women served through NBCCEDP.

Many deaths from breast and cervical cancers could be avoided if cancer screening rates increased among women at risk. Deaths from these diseases occur disproportionately among women who are uninsured or underinsured. Mammography and Pap tests are underused by women who have no source, or no regular source, of health care; women without health insurance; and women who immigrated to the United States within the past 10 years.[1]

Women Screened Through the NBCCEDP, by Program Year
July 2001 to June 2006
National Aggregate

Women screened (received an NBCCEDP-funded Pap test, mammogram, or clinical breast exam)

Women who received an NBCCEDP-funded mammogram

Women who received an NBCCEDP-funded Pap test

Program year (PY) is defined as July 1 through June 30.
For example, 'PY04' represents July 1, 2003 through June 30, 2004.

CDC has invested in developing a system to achieve efficiency in the NBCCEDP and to address the relative stability of funding allocations. The system includes a performance-based approach to making funding decisions. CDC continues to refine this approach, which ensures that funds will be distributed appropriately to programs, based on the programs' ability to comply with program guidelines; provide high-quality care to the largest number of low-income, uninsured women; and maximize available funds.

IASWR is a nonprofit national organization whose mission is to advance social work practice and education and to inform health and social policy through research. Five major national social work organizations: the Association of Baccalaureate Social Work Program Directors, the Council on Social Work Education, the Group for the Advancement of Doctoral Education, the National Association of Deans and Directors of Schools of Social Work, and the National Association of Social Workers founded IASWR. IASWR promotes and facilitates scientific testing and evaluation of health and social service interventions and programs and promotes empirically documented, effective interventions in social work practice. (www.iaswresearch.org).

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Project SAFe Executive Summary

Project SAFe tested a systematic evidence-based patient navigation/case management approach to improve patient cancer screening follow-up adherence. The target population was medically under-served low-income, ethnic minority women with abnormal breast and cervical screens. Controlled clinical trials had demonstrated the efficacy of interactive health education counseling and systems navigation for improving abnormal screening follow-up adherence. The SAFe project adapted these interventions for delivery in different service systems and diverse populations, added mental health screening and assessment, and included more intensive psychosocial counseling for women with special needs. Key study questions concerned: the effectiveness, feasibility and utility of SAFe patient navigation/case management; identification of patient, provider and health systems barriers; and facilitating processes in implementing SAFe in "real world" health care systems. Tested in three separate studies in multiple sites, SAFe patient navigation/case management improved patient adherence significantly over site baseline rates, non-enrollee rates, and control group rates, with adherence rates improving from 6% to 25%. The project developed a SAFe Tool Kit for dissemination to community based clinics.

The Challenge: Why Was Project SAFe Developed?

Significant improvements have been made in providing breast and cervical cancer screening for low-income women. Unfortunately, low-income, minority women who are screened and found to have suspicious or abnormal mammograms are most likely to miss follow-up diagnostic test appointments or to be lost to follow-up, thereby effectively delaying diagnosis and treatment. This is of concern because later stage at diagnosis, morbidity, and mortality remain higher among low-income, minority women. Less than optimal or non-adherence rates to abnormal screening follow-up can be as high as 60% among medically under-served low-income, ethnic minority women.

Inadequate follow-up occurs when low-income women encounter health system, health provider, and personal barriers to optimal diagnostic follow-up. Low-income women are more likely to be uninsured or underinsured, to lack a regular source of medical care, and to receive fragmented screening, diagnostic resolution, and treatment services. Health systems serving these women may lack adequate patient tracking and record-keeping mechanisms, flexible appointment scheduling resources, and staffing resources. A breakdown in provider-patient communication due to time constraints and language and health literacy barriers may result in women never being adequately informed about their abnormal test or what specific follow-up is being recommended and why.

The health action a woman takes after being told that her screening test indicates a need for further testing or treatment will also be strongly influenced by: 1) her understanding of the meaning (and urgency) of the abnormal result; 2) what she believes is her risk of actually having cancer (including whether she has symptoms she believes are serious); 3) whether she believes that what is being recommended will make a difference (e.g., her perceptions about cancer prevention and survival); and 4) what problems, barriers, and costs she will face in following medical recommendations, such as perceived discomfort or embarrassment of follow-up procedures and difficulty in navigating fragmented systems of care and obtaining supportive resources. Women may be torn between wanting to know and being afraid to find out whether they have cancer. Women may take no action to learn the results of an initial screen or may place low priority on timely follow-up. Women's personal assessment of their cancer risk as well as their choice of health behavior may also be strongly influenced by culturally determined beliefs, psychological distress (e.g., depressed women have been shown to be diagnosed at a later stage and to be less adherent to diagnostic follow-up), competing health and psychosocial problems in their daily lives[31] and out-of-pocket costs, including time away from work.

Patient navigation/case management approaches are increasingly being used to promote patient adherence to recommended treatment and to monitor patient appointment keeping. Controlled clinical trials of patient navigation/case management interventions find that interactive counseling, education, monitoring and reminders, and resource navigation (in-person or telephonic) are effective in improving patient care management over usual care for a range of health conditions. **Controlled clinical trials have also shown that interactive health education counseling and systems navigation interventions significantly improve breast and cervical screening and abnormal screen follow-up adherence, particularly among low-income medically**

underserved populations. (See Table 1: Examples of Clinical Trials.) Several of these studies find that low-income and ethnic minority patients are most likely to need and to benefit from more intensive counseling plus systems navigation resources. **In general, the evidence provides convincing support for providing a combination of services at different levels of intensity and cost (e.g., written educational materials and appointment reminders, brief telephone reminders, and interactive counseling). Conducting an assessment of individual women's risk for nonadherence and implementing methods to match educational counseling and service intensity to individual patient need is likely to be effective and cost sensitive.**

Despite the very promising results of these studies, critical translational implementation and dissemination questions remain.

- Are these interventions effective across culturally diverse patient populations and diverse health care systems?
- What organizational resources and cost barriers affect providing these interventions in real world and sometimes under-resourced primary care and community clinic systems.
- What key intervention elements facilitate adherence and the efficient implementation of patient navigation/case management?
- Are there efficient and effective ways to match service type and intensity with individual women's needs?
- Which intervention elements can be standardized to facilitate their delivery and provider staff training?
- Which intervention elements are adaptable for diverse patient populations and health systems and which are optional?
- What is the cost of patient navigation/case management services?

Project SAFe was developed and supported under a CDC initiative aimed at addressing these unanswered questions within diverse health systems that provide abnormal screen follow-up for ethnically diverse and medically disadvantaged populations. A series of SAFe studies aimed to:

- Evaluate a multifaceted patient navigation/case management intervention that combined interactive assessment and individually tailored counseling and systems navigation to improve abnormal screen follow-up among low-income, ethnic minority women.
- Evaluate the feasibility of mental health screening, assessment, and referral within breast and cervical screening and diagnostic programs.
- Evaluate the effectiveness of SAFe among diverse populations and in diverse health care systems.
- Identify patient, provider, and health systems barriers and facilitating processes to implementing the SAFe patient navigation/case management model in "real world" health care systems.
- Identify cultural competency elements in SAFe patient navigation/case management.
- Develop case manager training materials, implement training of staff in different health care systems, and evaluate training outcomes.
- Examine the cost of SAFe intervention.

What is SAFe?

SAFe's **systematic evidence-based patient navigation/case management** approach to improve patient cancer screening follow-up adherence combines two effective interventions to reduce patient non-adherence to follow-up: interactive telephone assessment and counseling and systems navigation. Interactive telephone educational counseling, using trained patient navigators/case managers, has been proven effective in randomized clinical studies of women at high risk for non-follow-up after an abnormal cancer screen and in improving mammography adherence. Patient and Systems navigation was developed under the leadership of Dr. Harold Freeman at Harlem Hospital to assist patients in navigating the hospital and human services systems to achieve optimal follow-up for cancer detection and treatment. SAFe adapted each of these interventions for delivery in

different service systems and included mental health screening, assessment, and more intensive psychosocial counseling for women with special needs.

The SAFe patient navigation/case management service model provides patient-centered assessment and educational counseling, centralized interpersonal patient tracking, reminders, and follow-up assistance, and links to community resource programs. Individualized assessment of known barriers to follow-up determines the type of follow-up service plan – i.e., telephone reminders and interpersonal counseling. Interpersonal health education, counseling, skill enhancement in patient-doctor communication, and information about and assistance with the use of community based resources aim to empower women to act in their own best health interests. The goal is to improve diagnostic, treatment, and repeat screening adherence by enhancing women's health care utilization knowledge and coping skills. Links to community resources aim to facilitate women's access to services and effective clinic use of and communication with community based programs. Centering patient follow-up tracking, reminders, and counseling services under the responsibility of a designated clinic staff case manager aims to achieve systematic coordination of abnormal screen follow-up services and monitoring of patient adherence. To address the special needs and barriers to follow-up experienced by a minority of women (i.e., women diagnosed with cancer, women with depression or high anxiety and psychosocial stress), brief counseling and mental health referral is provided by an onsite or community based master's degreed social worker in collaboration with the case manager. The SAFe model closely parallels the CDC patient navigation/case management guidelines. A baseline clinical decision-making algorithm is used to distinguish the women that require more intensive follow-up interventions from those who do not, and to assign a level of service consistent with individually assessed barriers.

What Was Learned?

Evidence that SAFe is Effective in Improving Follow-up Adherence

- Tested in three separate studies in multiple real world service systems with diverse patient groups (multi-site pilot (n=753), randomized (n=409), and implementation (n=398) (see Table 2), SAFe patient navigation/case management **improved patient adherence significantly** over site baseline rates, non-enrollee rates, and control group rates, with rates of adherence improving from 6% to 25%.

- In most cases, receiving SAFe patient navigation/case management resulted in **significantly more timely adherence** over women receiving usual care as represented by site baseline, women never enrolled in the SAFe program, and randomized control group timeliness rates, with timeliness rates improving from 10% to 21%.

- In the SAFe randomized control trial, women receiving SAFe patient navigation/case management achieved equal or higher rates of both adherence and timely adherence across all classification categories for both mammography and PAP when compared to women in the control group. SAFe patient navigation/case management achieved the largest gains in both adherence and timely adherence for women with less severe initial screening classifications (ACR 3; LGSL).

- Adherence rates of women receiving SAFe patient navigation/case management were similar across ethnic groups.

- Improved adherence outcomes were achieved across urban and rural community based screening clinics, urban diagnostic and treatment medical centers, and geographic regions.

- Mental health screening identified 8-10% of women with depressive or anxiety disorders. These women and others with special needs achieved good adherence and were referred to community-based services.

- Rescreening rates were higher among women receiving SAFe services than non-enrolled women.

- Patient satisfaction with SAFe was high.

Evidence of Barriers to the Implementation of SAFe

- Significant percentages of women in all three studies ultimately could not be located. Random sampling of adherence rates for these women showed dramatically lower adherence rates.
- Difficulty in identifying women eligible for SAFe services in some systems. Depending on medical or nursing staff referral to the case manager failed to identify all women with an abnormal screen.
- Clinic system lack of a centralized patient tracking method resulted in failure to identify all women with an abnormal and required additional patient navigation/case management time in tracking women.
- Existing processes for informing women of their abnormal result did not routinely provide adequate or motivating information that led to prompt adherence. In some cases these processes were untimely and incomplete.
- Clinical time and staffing constraints resulted in delayed appointments for many women.
- Problematic transfer of patient information and communication between screening and diagnostic programs resulted in delayed follow-up and increased time of SAFe case manager.
- When the case manager is not viewed as a member of the clinic team, communication and other barriers impair efficiency and effectiveness.

Evidence Supporting Key Intervention Element

- Designating the patient navigator/case manager as a member of the clinic care team facilitates implementing SAFe.
- Integrating patient navigation/case management services with the process for informing women of results facilitates the patient navigation/case management service, improves time efficiency, and provides the opportunity to assess and counsel women on their understanding of the screen results, the subsequent diagnostic or treatment follow-up, and barrier reduction.
- Computerized appointment and results tracking improves follow-up and reduces patient navigation/case management service time.
- Routine interactive assessment of patient adherence barriers enables education and systems navigation counseling to be tailored for individual women. This is consistent with findings from other studies that tailoring educational and counseling messages is likely to be more effective.
- Standardized scripted assessment and counseling and service tracking methods facilitate patient navigation/case management staff training, service quality monitoring, and ongoing evaluation of service costs, and barriers encountered.
- Assessment can be used to assign different levels of service follow-up. In SAFe, the case manager used a clinical decision-making algorithm to determine women's assigned level of service intensity. The algorithm was based on assessment of patient barriers. The finding that there were no differences in adherence rates across service levels supported the effectiveness of this method.
- SAFe patient navigators/case managers maintained linkage with community based resources that facilitated systems navigation.
- Brief counseling and referral to appropriate community based services were provided for a significant minority of women (15%-24%) who were assessed as having special needs – being diagnosed with cancer or depressive or anxiety disorder or experiencing significant current psychosocial stress. These women achieved rates of adherence similar to that of women without these needs.
- SAFe case managers reported that the scripted assessment and counseling responses facilitated their work and that empowerment strategies were most frequently undertaken.
- Initial case manager training must be augmented over time by specific supervisory support within clinic programs or by linking with other case managers through a telephone network.

Evidence of Adaptations and Optional Intervention Elements in Different Health Care Systems

- Having a script in English facilitated translation into Spanish and was helpful in adapting elements for the Chinese-speaking patients. Thus, having scripted tools was helpful in adapting materials for different cultural groups and facilitated responses that were sensitive to health literacy issues.
- Counseling services for women with special needs were provided through different organizational arrangements within the different health systems in which SAFe was studied. It is possible to distinguish the cost of these services from general patient navigation/case management direct costs.

Evidence of the Cost of SAFe

Cost breakdown found that the case manager cost was $11/month for mammogram patients and $15/month for cervical patients, based on one year of service. Assuming an average of social work contacts ranging from 3-5 per patient, direct costs can be estimated using local hourly rates, which average $35/hour. These figures include the cost of extensive outreach efforts - an average of 6 phone attempts to yield one enrolled woman - when calls to the many women who were never reached were factored in. The annual cost represents direct activities (time spent in interaction with a woman or collaterals) and indirect activities (appointment tracking and paperwork) of the navigator and MSW, as well as supervisory and consultation time (to the navigator/case manager) for the MSW.

KEY PATIENT NAVIGATION/CASE MANAGEMENT INTERVENTION ELEMENTS

The following outlines the critical patient navigation/case management components that are based on existing clinical trial evidence. Programs planning to implement a quality patient navigation/case management program in their clinics should consider planning for each of these elements.

ORGANIZATIONAL REQUIREMENTS FOR PROVIDING SYSTEMATIC PATIENT NAVIGATION/CASE MANAGEMENT

Implementing effective patient navigation/case management requires organizational planning and preparation. Key elements include:
- **Assessment of Clinic Population Characteristics and Need**

  - Is there a need to improve the follow-up adherence of women in your program?
  - What are the socio-cultural characteristics of the women you serve - are they of predominantly low-income, of culturally diverse backgrounds, with limited health literacy?
  - Would your clinic population benefit from being linked to community-based resources?
  - Are there deficiencies in the current process of informing patients of abnormal results? Is the notification process centralized and systematic?
  - Could your current processes for patient tracking and appointment reminders be improved? Is this process centralized and systematic?
  - Could your clinic communication processes about patient follow-up among medical providers, with other provider systems, and with community programs be improved?
  - Is your program making optimal use of existing state and local community program resources?

KEY INTERVENTION ELEMENTS

In designing a patient navigation/case management program, individual programs should design their intervention model to meet specific needs of its patient population and to enhance its organizational service strategies. While individual adaptations are recommended, key elements are supported by existing evidence from SAFe and other clinical trials reviewed above.

- Empower a designated individual and group of individuals to assume leadership for implementing SAFe patient navigation/case management.
- Designate a patient navigator/case manager.

- Develop a routine structured patient navigation/case management protocol for your clinic that includes:
  - Integrating patient navigation/case management with results reporting
  - Routine patient tracking and written and telephone reminder system
  - Scripted or structured assessment to identify women at risk for poor adherence to follow-up
  - A method to match follow-up service intensity with a woman's assessed risk of nonadherence
  - Barrier and educational counseling guidelines
  - Systems navigation and community resource linkages
  - Cultural competency elements
  - Service guidelines for women with special needs

- **Review your Patient navigation/case management Protocol in Relation to the Centers for Disease Control Patient navigation/case management Policy**

The SAFe Tool Kit: An Adaptable Resource for Patient navigation/case management Practice

The SAFe Tool Kit can be adapted for a specific service system or community based clinic or can be used to modify patient navigation/case management practice already in practice. The Tool Kit provides guidelines for assessing need, planning, and staff preparation. Training materials can be self-administered and adapted to the specific care system. Individual elements of the SAFe Patient navigation/case management Model can be selected for implementation and others can be adapted. Materials and tools can be used as resources to adapt or modify patient navigation/case management materials already in use. The Tool Kit includes resources related to each element of the CDC Patient navigation/case management Policy.

Table 1: Clinical Trials of Patient navigation/case management Interactive Counseling and Systems Navigation

Reference	Patient Group	Health System	Targeted Behavior	Key Interventions	Comparison Group	Outcome
Hunkeler et al., 2000	302 adult primary care patients	HMO	Improve depression care management	Emotional support and focused behavioral interventions in 10 6-minute tel calls over 4 months by clinic RNs	Randomized control	Intervention patients experienced clinically significant improvement at 6 weeks and at 6 months and reported greater satisfaction with care
Piette, et al., 2001	272 VA patients with diabetes	VA general medical and diabetes clinics	Glycemic control and serum glucose testing	Automated telephone patient assessment (touch-tone key-pad); RN telephone ed. and follow-up calls; RN communication with PMD	Randomized control	HbA_{1c} levels lower and fewer symptoms, and greater satisfaction with care in intervention group
Resnicow, et al., 2001	1011 pre-dominantly African-Am women	14 churches	Increase fruit and vegetable intake	3 intervention conditions: comparison, self-help intervention with 1 tel cue call, and self-help with 1 cue call and 3 motivational counseling calls	Churches were randomized	Improvement was significantly greater in the motivational interviewing group than in the comparison and self-groups
Riegel, et al., 2002	358 Older adults with chronic heart failure, 25% Spanish speaking	MD Practices	Facilitate patient care for chronic heart failure	Standardized telephone assessment, ed, counseling, monitoring, resource info; length of intervention – 6 mo.	Randomized control	HF hospitalization rate 45.5% lower in intervention group, hosp days and multiple readmissions significantly lower; cost saving realized
Tutty, et al., 1999	122 primary care adults	HMO	Facilitate depression care and increase adherence to antidepressant medication use	Tel counseling and support over 6 weeks; written educational materials	Contemporaneous control group	Tel counseling patients had significantly lower depressive symptoms at 3 and 6 months and were 2x more likely to adhere to antidepressant medication
Bowland, L et al., 2003	216 women; 55% having completed high school	Breast screen center Australia	Psychological distress associated with screening mammography	Tel or in-person home visit counseling	Randomized groups: tel, vs in-person, vs usual care	Receipt of counseling was associated with significantly better psychosocial functioning; 32% or women randomized to home visit refused in-person counseling, only 1% refused tel counseling
Champion, et al., 2003	803 low-income African-American	HMO gen med	Mammography screen	Standardized assessment, telephone and in-person counseling	Randomized control and more modest intervention groups	Personal and telephone counseling increased adherence 60%-50%
Costanza, et al., 2000	1655 underusers of mammography age 50-80	HMO	Mammography screen	Barrier specific telephone counseling, up to 3 calls of average duration of 5.5 minutes; physician education; reminder control condition	Randomized control	BSTC was effective and MD education was marginally effective for women who had prior but not recent mammograms; cost was $726 per additional regular user
Crane, et al., 2000	4,000 women age 50 or more	Low-income and minority neighborhoods	Mammogram	Telephone assessment and barriers counseling plus follow-up counseling calls	Non-randomized intervention group; a cohort group randomized to either single tel call, usual care, or single call	27% of intensive tel intervention patients obtained mammogram within 6 months vs 11-16% in randomized cohort
Duan, et al., 2000	813 ethnically diverse urban women	30 churches	Annual mammogram	Individualized annual ed and behavioral tel counseling; conducted for 2 years	Randomized church groups	Among tel counseling recipients, mammography adherence was maintained among baseline-adherent participants; reduced nonadherence rate from 23% to 16%
Engelstad,	108 women,	Public	Abnormal	Women notified of results by	Randomized	Of women in intervention group, 65%

et al., 2002	80% ethnic minority		cervical screen follow-up	tel; RN case manager made reminder calls before and after each appt and missed appt; computerized tracking	control	vs 41% in controls kept at least one follow-up appt by 6 months; 50% of intervention vs 19% of controls had 6 mo follow-up and diagnostic resolution in 18 mo.
Engelstad, 2002	348 low-income African-American and Hispanic women with abnormal pap screen	Urban public medical center	Abnormal follow-up test by 6 months	Standardized barrier assessments; individually tailored education, system navigation, counseling, and referral; systematic tracking system	Randomized control group	62% follow-up by 6 mo vs 35% in control group; no follow-up for 25% of intervention group vs 65% of control group
Freeman, et al., 1995	131 screening patients and 77 cancer patients; 64% African-Am and 26% Hispanic	Harlem Medical Center	Abnormal follow-up diagnostic biopsy	Designated navigator, tracking forms, outreach through diagnosis and psychosocial support for patients with cancer	Non-randomized group of patients who never received systems navigation	85.7% of patients receiving the intervention completed biopsies vs 56.5% of non-navigated; 71.4% vs 38.5% completed
Janz, et al., 1997	460 women age 65-85, nearly 24% African-American	Primary care practices	Mammogram	MD letter; standardized tel counseling by peer for woman who did not respond within 2 months	Randomized control group	39% in intervention group vs 16% in control group obtained confirmed mammogram
Lipkus, et al., 2000	1,099 women	HMO	Mammograms on schedule	Tailored telephone counseling; tailored print communications; usual care	Randomized control group	Tel counseling resulted in 71% vs 61% for usual care; tailored print resulted in 67% ; tel counseling was particularly effective among previously nonadherent women
Marcus, et al., 1992	>=25% African-Am, >+25% Hisp, >+25% non-Hisp White		Completion of at least 1 visit for abnormal smear		Randomized control group	
Marcus, et al., 1998			Completion of at least 1 visit for abnormal smear, invasive ca		Randomized control group	
Melnikow, et al.,	243 uninsured or Medicaid; 9% African-Am, 15% Hispanic	Family planning clinics	Abnormal pap test follow-up	3 telephone reminder calls	Retrospective cohort, no comparison group	Overall adherence rate was 56%; 39% after 1 tel contact with improvement after 2-3 tel contacts
Miller, et al., 1997	828 English-speaking, predominantly low-income, 86% African-American, with abnormal pap test	Clinics	Initial & 6-month diagnostic follow-up	Scripted telephone counseling; telephone counseling + booster tel counseling at 6 months; tel confirmation	Randomized to 3 intervention groups or usual care group	Telephone counseling increased initial adherence over both tel confirmation and UC (76% vs 68% or 50% and increased 6-month follow-up 61% vs 36% and 30%
Taplin, et al., 2000	1765 women who had not scheduled a mammogram; majority with high school or greater ed and middle or upper income	HMO	Adherence to mammography screening	3 intervention groups: a reminder postcard, reminder tel call, a motivational tel call addressing barriers; tel callers could schedule mammography	Randomized 3 intervention groups	Tel calls increased scheduling of mammogram; no difference in type of call; higher income associated with greater adherence
Thompson, et al., 2002	196 women age 50-74	Inner city public health hospital	Mammogram within 8 weeks	RN prompt and barrier specific counseling, video, pamphlet, reminder call, bus tokens	Randomized group	49% of intervention women had mam vs 22% of controls

Weber & Reilly, 1997	376 patients, age 52-77, who had not had mammogram in at least 2 years; ethnically diverse	Urban teaching hospital	Mammogram	Culturally sensitive, interactive pt ed, reminders, and systems navigation; designated community health education; practice based data managers maintained clinical database and provided reports to PMD, MD; sequenced level of intervention - reminder letter, 3 tel calls, letter 2, CHE home visit	Randomized control group	Women in intervention group were nearly 3 times as likely to receive a mammogram; benefit persisted across age, race, and prior screening behavior

Table 2: Project SAFe Studies

Ref	Patient Population	Health System	Targeted Behavior	Key Interventions	Comparison Group	Outcomes
Ell, et al., 2002a	605 low-income, ethnic minority women; 71% Latina, 18% African-American	Urban public sector diagnostic and treatment medical center and academic health center	Diagnostic and treatment follow-up for abnormal mammogram – ACR 3-5	Individualized barrier assessment and counseling; systems navigation; more intensive counseling for women with cancer, depression or anxiety and significant psychosocial stress	Contemporaneous group of non-enrolled women at both sites	Adherence rates to diagnostic resolution and initiation of treatment for women with cancer were 93% and 90% at the respective study sites; adherence for women who could not be located or who refused study consent were 72% and 69%; timely adherence was significantly better among women served; patient satisfaction was high
Ell, et al., 2002b	196 low-income, predominantly Latina women	Public sector diagnostic center	Diagnostic and treatment follow-up for abnormal screen – LGSIL, HGSIL	Individualized barrier assessment and counseling; systems navigation; more intensive counseling for women with cancer, depression or anxiety and significant psychosocial stress	Contemporaneous group of non-enrolled women	Adherence to at least 1 follow-up appointment was 93% for intervention HGSIL patients vs 67% for non-enrollees and 83% for LGSIL vs 58%; over 1 year, 61% of women with HGSIL were fully adherent and 41% of women with LGSIL were fully adherent; 93% of women were mostly or very satisfied with SAFe services; cost of intervention was $319 per enrolled woman for 1 year of service
Ell, et al., 2002c	753 low-income ethnic minority women	Urban public sector diagnostic and treatment medical center and academic health center	Screen and assess for depression and anxiety	Individualized barrier assessment and counseling; systems navigation; more intensive counseling for women with cancer, depression or anxiety and significant psychosocial stress	Comparison between women with and without depression or anxiety disorder	10% (n=74) met criteria for depressive or anxiety disorder. 47 women with disorders were receiving no depression care. Women with depressive or anxiety disorders were more likely to have cancer, significant psychosocial stress, fair or poor health status, a comorbid medical problem, and functional limitations; adherence between women with disorder and without disorder did not vary significantly
Ell, et al., 2003	371 low-income pre-dominantly Latina	Public sector diagnostic center	Abnormal breast or cervical screen follow-up	Individualized barrier assessment and counseling; systems navigation; more intensive counseling for women with cancer, depression or anxiety and significant psychosocial stress	Randomized control group of patients who had been informed of abnormal result and importance of follow-up through the informed consent procedure and randomly selected group of non-enrolled women	Adherence to follow-up for all intervention patients was significantly higher- 88% vs 74% for control patients and 63% for non-enrolled; ACR3 adherence was significantly higher- 87% vs 55%, but not for ACR4-5 (96% vs 93%); timely adherence for breast patients was significantly higher- 50% vs 38% for control patients and non-enrolled patients; there were no significant differences in adherence rates for pap follow-up between

						intervention and control patients (86% vs 84%) but there were significant differences between intervention and control patients (86% vs 60%)
Ell, et al., 2007	204 low-income, ethnic minority women	public medical center	Abnormal breast screen follow-up	Individualized barrier assessment and counseling; systems navigation; more intensive counseling for women with cancer, depression or anxiety and significant psychosocial stress	Study clinics baseline follow-up rates	Intervention group was much more likely to reach diagnostic resolution than the control group (90% vs 66%, OR= 4.48, p<.001). Intervention effectiveness was not significantly different for women assigned to different levels of service intensity.

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The SAFe PATIENT NAVIGATION/CASE MANAGEMENT TOOL KIT

This Patient navigation/case management Tool Kit is a guide for health system administrators, providers, and cancer screening case managers. Specific sections detail the background and targeted aims of SAFe, and describe how to assess your program's need for SAFe, how to implement SAFe in your health care system, and how to evaluate SAFe service outcomes and monitor service quality. These tool kit materials address each of the seven elements of the Centers for Disease Control and Prevention patient navigation/case management policy (CDC 2000). Each tool kit section is tabbed and has a table of contents for ease in referencing.

Section I. An Overview of Non-Adherence and Interventions to Improve Adherence and Quality of Care
--- an overview of the problem of non-adherence to follow-up, barriers to adherence, and interventions to improve adherence.

Section II. Strategies SAFe Program Goals, Target Population, Elements, Effectiveness, and Cost
--- provides an overview of specific aims, key elements, and evidence of effectiveness and cost.

Section III. State Program Directors Implementation

Section IV. Administrative Steps Prior to Initiating SAFe Patient navigation/case management
--- guides clinic or health system administrators in answering key questions – What aspects of our organized system of care would be improved by patient navigation/case management services? Would adherence to follow-up be improved in our clinic by the addition of SAFe patient-centered patient navigation/case management? How would patients be selected for patient navigation/case management? What resources should be allocated to follow-up adherence patient navigation/case management? How would we go about preparing for and then implementing SAFe?

Section V. Patient navigation/case management the SAFe Way: A Structured Program Manual
--- provides case managers and health system administrators a detailed step-by-step guide for providing SAFe patient navigation/case management intervention, including examples of options for program elements that provider programs might wish to consider in tailoring their SAFe program to meet local program needs.

Section VI. Evaluation and Quality Monitoring Guide
--- guides health system administrators and case managers in implementing program evaluation and monitoring patient adherence as well as organizational and patient barriers to providing SAFe patient navigation/case management.

Section VII. Case Manager Training Guide, Training Exercises, and Pre- Post-Test
--- includes training vignettes and content that are designed to be used as a self-administered guide.

Section VII. Program and Data Collection Tools and CD-ROM

Chapter 1

PATIENT NON-ADHERENCE AND INTERVENTIONS TO IMPROVE PATIENT ADHERENCE AND QUALITY OF CARE

Contents

The Challenge: Non-Adherence to Cancer Screen Follow-up

> The Burden & Costs of Non-Adherence
> What are the Barriers to Screening Follow-up among Low-income Women?

Solutions: Interventions to Improve Access and Adherence

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> Organizational Modifications – Delivery System Design

Patient navigation/case management

Quality of Care Intervention for Women with Special Mental Health Needs

References

NON-ADHERENCE TO CANCER SCREEN FOLLOW-UP AND INTERVENTIONS TO IMPROVE PATIENT ADHERENCE AND QUALITY OF CARE

THE BURDEN AND COSTS OF NON-ADHERENCE

Medical non-adherence is a significant public health problem, a financial burden to the nation's health care system, and a source of ongoing frustration to medical providers. Adherence is a key predictor of medical outcomes. For example, the incidence and mortality of late-stage breast and invasive cervical cancer have decreased steadily over the past three decades in the United States, in part due to more women adhering to recommended screening guidelines. However, later stage at diagnosis and the related morbidity and mortality remains significantly higher among low-income, ethnic minority, medically underserved women. Breast and cervical cancer screening can improve survival only if screening results in detection and treatment at an early stage of disease. Key factors in achieving early diagnosis are routine patient screening and effective management of abnormal screens through reliable patient follow-up.

> Partial or non-adherence to abnormal screening follow-up can range as high as 60% among medically under-served low income women, particularly among women from ethnic minority groups.

> Low-income, ethnic minority women who are screened and found to have suspicious or abnormal mammograms or Pap test results are most likely to repeatedly miss follow-up diagnostic test appointments or to be lost to follow-up, which can result in delaying treatment at an early stage.

> Medically underserved women also are less likely to obtain recommended repeat follow-up screening.
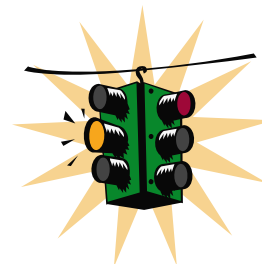

WHAT ARE THE BARRIERS TO SCREENING FOLLOW-UP AMONG LOW-INCOME WOMEN?

> *Patient, provider, and health care system factors can affect patient follow-up. It is well known that how people use health care and how patients make decisions about whether to follow medical advice is influenced by individual beliefs and perceptions in combination with environmental resources or barriers. Low-income and ethnic minority populations are most likely to encounter multiple barriers to adherence, including access, health system, and personal barriers.*

> **Access and Health System Barriers**

Low-income women are likely:
- To be uninsured or underinsured;
- To lack a regular source of medical care or to be linked to a specific primary care clinician – resulting in lack of continuity of care;
- To require assistance from community-based programs;
- To receive care in systems in which barriers to communication are common – lack of culturally and linguistically competent staff, lack of effective and efficient methods of giving patients

information and transferring information among multiple medical providers – preventing good patient-doctor communication and patient-centered care;
- To receive care in different care systems - resulting in fragmented screening, diagnostic resolution, and treatment services and lack of patient-centered continuity of care; and
- To receive care from under-resourced publicly funded health systems – potentially impeding receipt of timely screening follow-up services.

⊹ Personal Barriers

The health action a woman will take after being told that her mammogram or Pap test requires further testing or treatment can be strongly influenced by:
- What she was told about testing, what she understood the recommendation to mean, and her knowledge about the purpose and nature of follow-up procedures and the effectiveness of cancer treatment;
- What she believes is her risk of actually having cancer (including whether she has symptoms she believes are serious);
- Whether she believes that what is being recommended will make a difference in her health and what she perceives to be the risks of recommended follow-up – e.g., pain, embarrassment, loss of fertility;
- Whether she is excessively anxious - torn between wanting to know and being afraid to find out whether she has cancer – leading to avoidance behavior;
- Whether she is significantly depressed;
- Whether she is experiencing competing priorities or life stresses – e.g., other physical illness, having significant care-giving or inflexible work responsibilities;
- Whether she lacks support for follow-up, because family members and friends do not encourage or assist her (if needed) in getting follow-up care; and
- Out-of-pocket costs of follow-up – e.g., copays, lost work time, transportation.

WHAT INTERVENTIONS IMPROVE ACCESS AND ADHERENCE?

> *To address access and adherence barriers, screening and diagnostic programs are currently finding it necessary to implement financing, health system-design, and patient-focused strategies aimed at ensuring access to services for under-served women that will result in timely diagnostic resolution, initiation of treatment, and subsequent repeat screening.*

⊹ Financing Services to Reduce Access Barriers.

NBCCEDP state-partnered programs and local health programs are required to identify and secure diagnostic and treatment services following screening, using various strategies that ensure access to needed care: meeting contractual requirements that screening providers arrange for diagnostic and treatment services before screening women; making arrangements with state professional associations and health care provider groups to provide free or reduced-cost services; and billing public or private insurance whenever possible.

⊹ Delivery System Design – Quality of Care Improvements in the Organization of Care.

Primary care programs have begun to implement strategies to organize care for patients with an abnormal cancer screen. Each of these improvements has been found to be effective.

- **Clinical Information –** written educational materials

- **Computerized Patient Tracking Systems --** systematize appointment reminders, either manually or through the use of computerized tracking systems, and systematize patient notification of abnormal results

---

These services have significantly enhanced adherence, particularly among women who are less resistant to follow-up. Unfortunately, written educational materials and low-cost mailing and reminder interventions alone are less effective among women with special needs, including those with health illiteracy (lacking knowledge about cancer prevention and early treatment and about use of health services). Provider systems report problems in their processes for informing women of an abnormal screen result either because the woman does not understand the information that is communicated or because the woman cannot be located. More intensive services are needed.

PATIENT NAVIGATION/CASE MANAGEMENT – A QUALITY OF CARE IMPROVEMENT STRATEGY

Patient navigation/case management services are increasingly found to improve patient-centered primary care. Recognizing that personal barriers as well as women's ability to access services impede timely follow-up and treatment initiation, CDC recently provided national guidelines for patient navigation/case management services within NBCCEDP programs. SAFe patient navigation/case management includes the program components defined in CDC's current NBCCEDP patient navigation/case management policy:

- Assessment
- Plan
- Coordination
- Monitoring
- Resource development and linkage to community-based resources
- Evaluation

Local health care systems vary in their organization of care system design and vary with respect to whether or in what ways patient navigation/case management services are provided – i.e., routinely by a designated case manager or in an ad hoc manner by available clinic staff. Case managers may assist eligible clients in applying for public assistance programs; provide referrals to public hospitals or to county indigent-care programs; and facilitate arrangements with individual clients to pay reduced or full fees for services in negotiated payment plans. In many programs, case managers also provide more intensive or interpersonal efforts to address the education and support needs of high-risk women.

Patient Self-Management Support –

- patient-centered information, education, and follow-up reminders, written educational materials
- interpersonal health education, and emotional and problem-focused counseling (culturally sensitive)
- skill enhancement in systems navigation

Systems Navigation

- patient-centered systems navigation, communication bridging
- community resource linkage, use of a case manager

Quality of Care Intervention for Women with Special Mental Health Needs

> *To address the special needs and barriers to follow-up experienced by a minority of women (i.e., women diagnosed with cancer, women with depression or high anxiety and psychosocial stress), brief counseling and mental health referral is provided by an onsite or community based master's degreed social worker in collaboration with the case manager.*

Why Expand NBCCEDP to Include Mental Health Services?

- There are major disparities by ethnic group and socioeconomic status in access to and use of mental health services, particularly for depression.
- The WISEWOMAN expansion of NBCCEDP to include cardiovascular screening and intervention is a model for including mental health services for the medically underserved.

Why Integrate Mental Health Care Screening and Patient navigation/case management Services for Women with an Abnormal Cancer Screen?

- Psychological distress is a barrier to medical adherence.
- Rates of depression and anxiety are particularly high among low-income women.
- A significant number of women with cancer have major depressive disorder that is undetected or inadequately treated.
- There are effective medication and counseling treatments for depression.
- Access to mental health care among low-income and ethnic minority women is inadequate.
- Detection of depression requires active screening to improve detection and access to guideline care within primary care as recommended by the US Preventive Services Task Force (2002), www.ahrq.gov/clinic/uspstfix.htm.
- There are available effective screening tools that can be administered by physicians, nurses, and lay personnel.

Feasibility of Providing Mental Health Services in SAFe

- There is evidence that mental health services in SAFe are acceptable to most women.
- Providing mental health patient navigation/case management services within SAFe has been found to be feasible and to not add significant cost to SAFe patient navigation/case management.
- Primary care programs that serve low-income populations can seek funding under the current Health Resources and Services Administration, DHHS public-private initiative - Health Disparities Collaborative in Depression Care in community-based clinics (www.healthdisparities.net). Launched in 2000 with nearly 40 programs already active, the

initiative calls for a multifaceted depression care model for medically underserved in community-based primary care programs. Patient navigation/case management and problem-solving counseling are included in the currently disseminated model. The PHQ-9 screening instrument used in SAFe is also included in the model.

Relevant Literature

Adherence and Interventions to Improve Adherence

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CASE MANAGEMENT

THE SAFe WAY

SCREENING ADHERENCE FOLLOW-UP (SAFe)

SAFE Aims and Key Elements

Section II

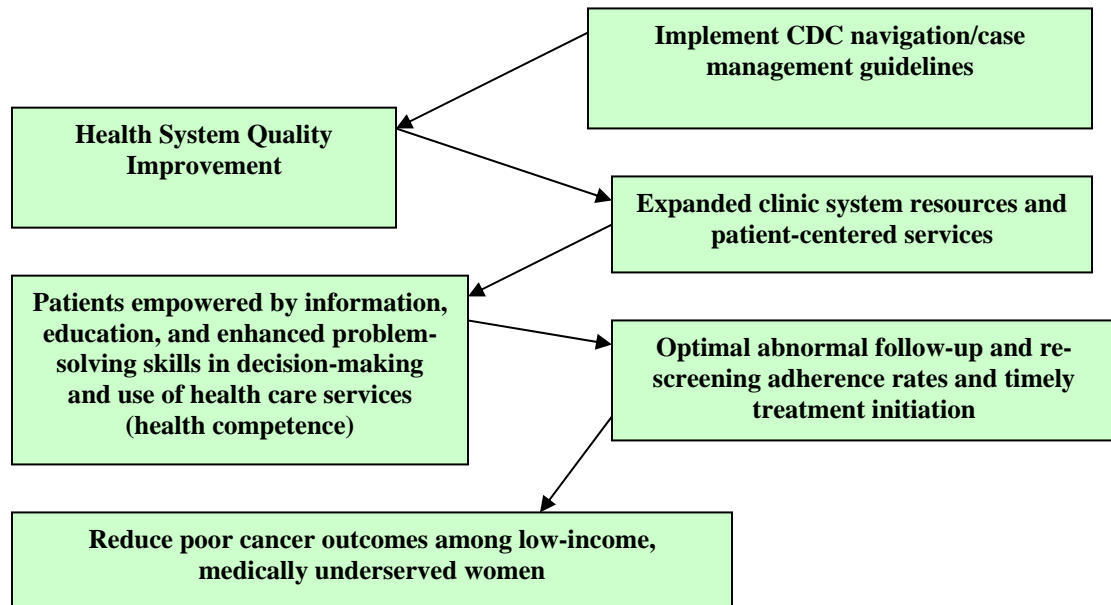# SAFe PROGRAM GOALS, TARGET POPULATION, ELEMENTS, EFFECTIVENESS, AND COST

Contents

WHAT ARE THE OVERARCHING GOALS OF SAFE?

SAFe is aimed at improving abnormal screen follow-up adherence by improving the quality of care provided for low-income women and by enhancing women's health care decisions and utilization skills. Ultimately, these goals are aimed at reducing poor cancer incidence and mortality outcomes among medically underserved populations.

Health System Quality Improvement	**Implement CDC navigation/case management guidelines**
Patients empowered by information, education, and enhanced problem-solving skills in decision-making and use of health care services (health competence)	**Expanded clinic system resources and patient-centered services**
	Optimal abnormal follow-up and re-screening adherence rates and timely treatment initiation
Reduce poor cancer outcomes among low-income, medically underserved women	

WHAT ARE THE SPECIFIC AIMS OF SAFE?

⊞ To Improve Patient Adherence Behaviors

SAFe is designed to be seamlessly integrated within existing health systems to reduce barriers to adherence with effective services (patient-centered and health care and community resource system navigation) and related delivery system modifications to achieve timely diagnostic follow-up and initiation of treatment, and to improve rates of repeat screening.

⊞ To Empower Women and Increase Their Health Competence

SAFe aims to enhance patient centered care. The aim is to influence women's follow-up adherence behavior by enhancing their knowledge and coping skills related to their medical decision-making and use of health care services. Interpersonal individualized counseling is aimed at influencing lifetime health behaviors, including to foster repeat screening behavior and good follow-up adherence if a woman experiences a future abnormal screen.

✛ To Provide Culturally Responsive Services

SAFe aims to provide culturally sensitive and to the degree possible, culturally competent services. These services are tailored to improve cancer outcomes among ethnic minority populations.

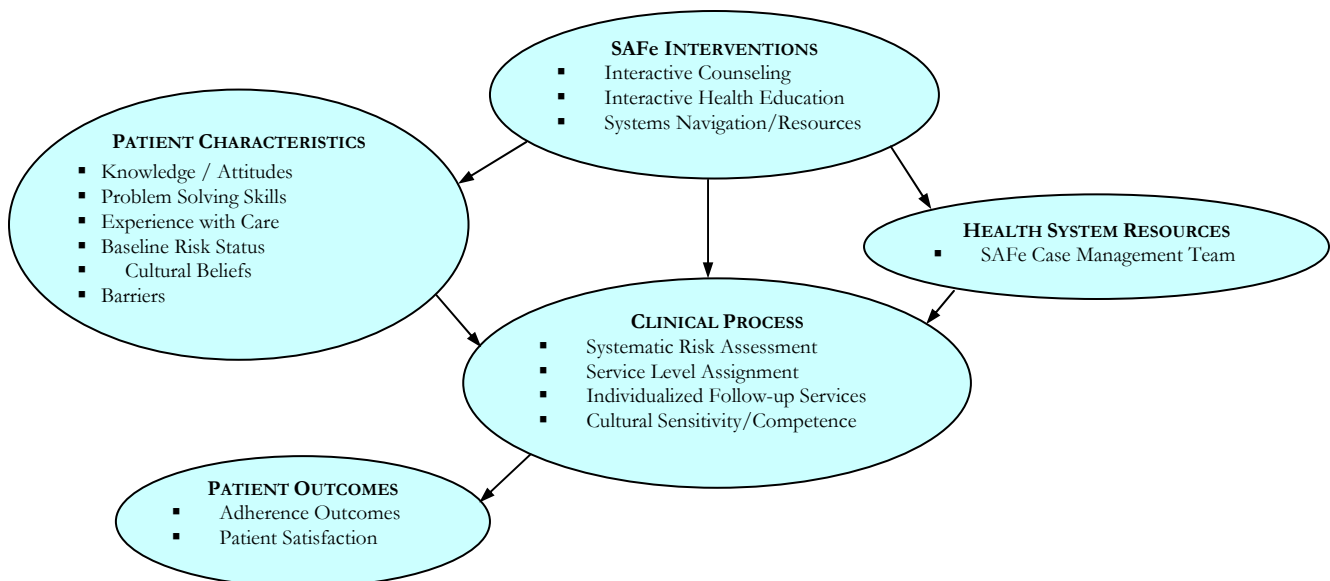### ✛ To Improve the Quality and Efficiency of Follow-up Care

Providers who want to improve the rates of adherence and the efficiency and cost-effectiveness of patient follow-up services might elect to implement SAFe as a Quality Improvement (QI) service.

- Enhance efficiency in follow-up by systematically implementing and integrating the service with usual clinic care systems.

- Be tailored to meet the needs and resources of local service system organizations.

- Facilitate quality monitoring and service data collection by providing structured assessment, planning, service level, community resource links, quality monitoring, and evaluation tools that yield systematic data on the characteristics of patients with specific needs and their adherence behaviors and on organizational barriers to optimal follow-up.

- Facilitate case manager training by providing self-administered training materials.

✛ To Enhance Clinic Access to Community Resources

Providers who want to improve patient's access to and use of supportive community resources will assign the responsibility of linkage to community-based programs to the SAFe case manager.

The SAFe Quality Improvement Model

SAFe INTERVENTIONS
- Interactive Counseling
- Interactive Health Education
- Systems Navigation/Resources

PATIENT CHARACTERISTICS
- Knowledge / Attitudes
- Problem Solving Skills
- Experience with Care
- Baseline Risk Status
- Cultural Beliefs
- Barriers

HEALTH SYSTEM RESOURCES
- SAFe Case Management Team

CLINICAL PROCESS
- Systematic Risk Assessment
- Service Level Assignment
- Individualized Follow-up Services
- Cultural Sensitivity/Competence

PATIENT OUTCOMES
- Adherence Outcomes
- Patient Satisfaction

WHO CAN USE SAFe?

State Programs.

SAFe addresses the national mandate and guidelines of the NBCCEDP and of state partnered programs for under-served populations. However, many low-income women are not eligible or do not receive NBCCEDP or similar state-sponsored services. These women may seek care in local community-based programs and are likely to benefit from SAFe case management services.

Screening, Diagnostic, and Treatment Service Providers.

The SAFe intervention model can be used by screening, diagnostic, and treatment service providers who serve less educated, low-income women from different cultural backgrounds. The SAFe model can be creatively modified for implementation in community-based screening programs, managed care organizations, university medical centers, and physician practices. SAFe can be system tailored to augment and to be integrated with existing provider follow-up services, such as tracking and appointment reminder systems, organizational processes by which women are informed of abnormal results, and case management.

Navigators/Case Managers.

Designated navigators/case managers will find that SAFe tools can be adapted for local needs and will facilitate implementation, evaluation, and ongoing training needs.

WHAT IS SAFe NAVIGATION/CASE MANAGEMENT?

A Systematic Approach to Women with an Abnormal Screen

> *SAFe is a systematic service approach designed to improve adherence to abnormal screen diagnostic and treatment follow-up and to influence women's future health care decisions and use of health services. The elements of the intervention are based on theory about health care use, sociocultural theory, and evidence from research.*

ⵣ Theory-Based

Health Belief Models. Key elements to explain patient adherence behavior drawn from Health Belief Models guide SAFe intervention: women's beliefs about the nature and severity of the health threat, perceptions of barriers or the perceived costs of taking action to reduce the threat, perceived benefits of taking such an action, and cues to action or reinforcements to specific behaviors. From this theoretical perspective, women's access and adherence to medically recommended follow-up care are seen as occurring as a result of the interactions they have with doctors, nurses, and other health system staff, the ways in which the health system organizes the care they need, and their ability to access the care.

Thus, SAFe is tailored to affect access and adherence to follow-up by influencing the predisposing (knowledge and attitudes), reinforcing (social support and cues to action), and enabling (assistance in barrier reduction) factors. This provides the theoretical rationale for interventions aimed at enhancing women's relevant health knowledge, problem-solving, and self-management skills, reducing psychological distress, and knowledge regarding the availability of adequate resources to cope with health threats.

Socio-cultural Explanatory Theory. SAFe also addresses cultural and social-contextual factors aimed at influencing the clinical care process. Thus SAFe aims to facilitate communication of information between physician and patient through the "bridging intervention" of the SAFe case manager. Similarly, the CM will influence systems and community resource navigation, and provide treatment and follow-up reminders through supportive reinforcing informational messages. SAFe also includes specific elements to enhance its socio-cultural compatibility and competence. Thus SAFe is based on an understanding of the cultural beliefs, practices, and preferences of patients and their families so that a "fit" can be attained between the needs of patients and the services provided. SAFe training materials support and encourage case managers to respect patient beliefs and preferences.

ⵣ Combines Evidence-Based Interventions

SAFe's interpersonal case management uniquely combines interventions already known to be effective and provides these based on routine assessment and planned service level assignment to maximize efficiency and to be sensitive to cost concerns.

To address multiple patient and health system barriers to follow-up, SAFe includes patient and systems focused interventions. Patient-centered education and counseling by peers and health professionals that addresses educational, psychological,

and practical barriers to optimum follow-up, and health care systems navigation and concrete assistance have been shown to be more effective than mailed or telephone reminders alone for women who are less likely to obtain recommended follow-up services. Counseling interventions that address emotional and culturally based concerns are more effective than is health education alone. Individualized health messages are found to be more effective than universal messages. Use of non-physicians to augment standard physician care and to assist patients to navigate the health system and to use community resources is also shown to be effective.

WHAT ARE THE KEY SERVICE ELEMENTS OF SAFE?

> *SAFe navigation/case management is guided by a highly structured intervention protocol that is designed to be an efficient way to routinely provide interpersonal assessment, information and education, and to "triage" or match abnormal screen case management service type and intensity to a woman's individually assessed needs.*

- ♣ **Designated clinic staff navigation/case management provider**

- ♣ **Patient-centered, telephone-based, culturally responsive, individualized interpersonal communication**

- ♣ **SAFe integrated with routine notification of abnormal results**

- ♣ **Routine assessment –**

  - To determine patients understanding of the medically recommended follow-up and of potential barriers to adherence
  - To triage patients to service type and frequency
  - To individualize the health education
  - To provide problem-solving counseling (in immediate response to identified barriers) to empower women

- ♣ **Interactive health education and problem-solving counseling**

  - Aimed at women's decision-making, empowerment, and health competence
  - Aimed at skill-building – how to formulate questions to ask doctor, how to use the healthcare system and community resources (systems navigation)

- ♣ **Systems navigation assistance and referral to community resources**

- Aimed at facilitating access to care and services

Interpersonal and written reminders, tracking, follow-up

- Case Manager provides follow-up assistance with environmental barriers and systems navigation, including patient-medical provider communication and resource referral until diagnostic resolution or initiation of treatment.
- "Booster" telephone calls to reinforce the health message and to address specific barriers to follow-up either until a diagnosis is made and/or treatment is initiated

Development of linkages and coordination with community based resources

- The case manager develops and maintains a community based resource file and actively maintains and develops the file and facilitates relationships with frequently used resources.

More intensive psychosocial services provided by a master's degreed social worker

- to address needs and barriers to follow-up experienced by a minority of women (with a diagnosis of cancer, depression or anxiety disorder, or severe psychosocial stress

Culturally sensitive services

- SAFe case managers should aim to provide culturally sensitive and, to the extent possible, culturally competent care. SAFe training materials address culturally sensitive services. All efforts should be made to provide case management services in the language of the patient, either by bilingual staff or through use of interpreters or family members.

EVIDENCE THAT SAFe IS EFFECTIVE

Combines Effective Counseling and Systems Navigation

SAFe was originally developed as an innovative combination of two successful models for intervention to reduce patient non-adherence to follow-up: interactive

telephone counseling and systems navigation. Interactive telephone counseling, using trained patient guides, has been proven effective in randomized clinical studies of women at high risk for non-follow-up after an abnormal breast or cervical screen. Systems navigation was developed under the leadership of Dr. Harold Freeman at Harlem Hospital to assist patients in navigating the hospital and human services systems to achieve optimal follow-up for cancer detection and treatment.

Additional recent studies confirm the positive effects of patient-centered counseling and systems navigation on patient adherence.

Studies of SAFe in Diverse Health Systems

The SAFe intervention has been tested in a recently completed progression of multi-site pilot (N=753), randomized (N=401), and implementation (N=350) studies funded by the Centers for Disease Control and Prevention [CDC]. Effectiveness of the intervention was assessed by examining rates of diagnostic follow-up adherence, timeliness of diagnostic resolution, timeliness of entry into cancer treatment, and rates of rescreening. These outcomes were tested against those of a randomized control group (in the randomized study) or non-enrollee comparison group (in the pilot and implementation studies).

In all three studies, adherence to diagnostic follow-up was higher among women who had received the SAFe intervention than in the comparison group, and rates of adherence ranged as high as 90% among intervention women with abnormal mammograms in the randomized study (versus 66% in the study's control group). The differences in adherence between those receiving and those not receiving the intervention were more pronounced in the women with less severe abnormal findings (ACR3 mammogram and non-HGSIL Pap results), suggesting that perhaps women with more severe findings (ACR4/5 mammograms and HGSIL Pap results) may already be more inclined to attend their recommended appointments due to the potential seriousness of the screen result. No differences in adherence among women receiving the SAFe intervention were found across ethnic groups, or in women with cancer or a diagnosis of depression or anxiety disorder. Thus, SAFe appears to be equally effective in helping these diverse groups of women. Further, use of the structured algorithm for assignment of service type and intensity was supported by the finding that there were no differences in adherence across assigned risk levels.

In general, women receiving the SAFe intervention also demonstrated higher rates of timely diagnostic resolution than those in their respective comparison groups. While this trend did not hold true across all categories of abnormal screen results in all studies, it does warrant further attention as (for example) the case managers in the randomized study were successful in improving the rate of timely diagnostic resolution among women with abnormal mammograms from 38% to 50%.

Evidence of Patient Satisfaction

Surveys of patient satisfaction with SAFe services found high rates of satisfaction with care.

⬛ Cost Analyses of SAFe

To generate a simplified overall direct cost estimate, the total program personnel costs (salary, fringe, and bilingual supplements) over a one-year period of the pilot were divided by the number of women enrolled and served during that time. Cost breakdown found that case manager cost was $11/month for mammogram patients and $15/month for cervical patients. Assuming an average of social work contacts ranging from 3-5 per patient, social work costs can be estimated using local hourly rates, which average $35/hour. These figures include the cost of extensive outreach efforts - an average of 6 phone attempts to yield one enrolled woman - when calls to the many women who were never reached were factored in. The annual cost represents direct activities (time spent in interaction with a woman or collaterals) and indirect activities (appointment tracking and paperwork) of the peer counselor and MSW, as well as administrative, supervisory, and other responsibilities of the MSW, who functioned as the SAFe program director on site.

PATIENT NAVIGATION/CASE MANAGEMENT

THE SAFe WAY

SCREENING ADHERENCE FOLLOW-UP (SAFe)

State Program Director Implementation Strategy

Chapter 3

State Program Director Implementation Strategy

Contents

How Can State Program Directors Facilitate Implementation of Structured SAFe Patient Navigation/Case Management?

Design a Dissemination and Implementation Strategy

Considerations in Planning

Provide Local Program Providers with Implementation Guidelines

Assist Clinic Programs to Assess their System Readiness

Identify, Inform, and Engage Key Stakeholders and Decision-makers in Dissemination Implementation Process

Consider Technical Assistance Strategies

Provide Guidelines for Quality Monitoring and Evaluation

How Can State Program Directors Facilitate Case SAFe Management?

➕ **Design a State Program Dissemination and Implementation Strategy**

- Provide funding for patient navigation/case management
- Provide navigation/case management guidelines
- Specify navigation/case management service expectations
- Provide state program leadership and technical assistance

➕ **Identify, Inform, and Engage Key Stakeholders and Decision-makers in Dissemination Implementation Process**

- Target guideline, funding, and service expectation dissemination materials to key decision-makers including clinic, program, and medical directors.

➕ **Provide Local Program Providers with Implementation Guidelines**

- Encourage clinics to assess their system of care, to identify problem areas, in structure of decision-making, communication processes in results notification and tracking, linkage to community resources.
- Distribute CDC Case Management Guidelines
- Encourage clinics to fully integrate case management with their system of care, to centralize notification of results process and to systematize patient tracking in "real time" rather than solely for data reporting purposes.

➕ **Consider Technical Assistance Strategies**

- Workshops
- Dedicated lead person
- Web-based materials, video cast

➕ **Provide Guidelines for Quality Monitoring and Evaluation**

- Provide quality monitoring tools
- Provide evaluation guidelines

Promoting better healthcare for women

PATIENT NAVIGATION/CASE MANAGEMENT

THE SAFe WAY

SCREENING ADHERENCE FOLLOW-UP (SAFe)

Clinic Administrator Manual

Section IV

The Health Service Provider Need Assessment, Implementation, and Problem-Solving Guide

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WOULD CARE IN YOUR CLINIC BE IMPROVED BY EVIDENCE-BASED NAVIGATION/CASE MANAGEMENT?

⬩ Assess Your Programs Needs

A health provider's decision to provide SAFe case management services should be based on an assessment of population and program need This should include an evaluation of the characteristics of the population being served and of actual follow-up behavior of the population served and a targeted assessment of existing program resources and organization of care.

Patient Population
- Is there a need to improve the follow-up adherence of women in your program?
- What are the socio-cultural characteristics of the women you serve - are they of predominantly low-income, of culturally diverse backgrounds?
- What is the health literacy level of your patient population?
- Would your clinic population benefit from being linked to community-based resources?

Delivery System Design
- Are there deficiencies in the current process of informing patients of abnormal results? Is the notification process centralized and systematic?
- Could your current processes for patient tracking and appointment reminders be improved? Is this process centralized and systematic?
- Could your clinic communication processes about patient follow-up among medical providers, with other provider systems, and with community programs be improved?
- Is your program making optimal use of existing state and local community program resources?

Patient Navigation/Case Management Services
- Do you have a specific case management plan?
- Do you have designated staff provide case management services? Are case management services fall under clear administrative lines of responsibility?
- Are existing case management services fully integrated with your systems notification and patient tracking systems?
- Is your program actively facilitating referral to community resource programs to assist your patients?

Cultural Responsiveness
- Do you have an active service plan to provide culturally competent services?

⚑ Assess Whether SAFe is a Feasible Quality Improvement Program for your Health Care System

> *If you determine that you serve a population of women who are likely to change their behavior with individualized health and problem-solving interventions, SAFe provides an NBCCEDP program, another state program, or a local community program with specific advantages:*

SAFe Quality Improvement Elements

- It is highly structured (and therefore amenable to quality monitoring, evaluation, and cost analysis).
- It is designed to match follow-up service intensity with individual patient need.
- It is culturally appropriate.
- It includes assessment, case management service planning decision support, and already developed and field tested implementation materials.

Cost and Staffing

- How will SAFe case management be financed? For example, SAFe services might be financed under state case management procedure codes.
- What contractual arrangements can be implemented to purchase designated hours for MSW services? A medical center with an established social work department might incorporate SAFe within the customary services of that program.
- Specific SAFe program funding might be obtained from local private or public funding sources.

Augmenting Existing Organizational Practices with SAFe Case Management

- It is important to assess what SAFe services will add to what you currently provide?
- How will SAFe complement and be fully integrated with care systems already working well?
- Before determining whether SAFe should be implemented, it is important to be fully aware of what the program does not do. SAFe should be used **in conjunction with, not in lieu of**, effective methods to provide care based on current medical practice guidelines, i.e., physician prompts, computerized medical records and patient tracking.

⚑ Assess the Readiness of Your Program/Clinic System

- How will we implement SAFe in actual practice in the clinic?

- How will Navigator/Case Manager(s) access information about abnormal screen results?
- Who can be assigned the PN/CM role or do we need an additional staff member?
- How will the workload of existing staff be impacted?
- Is there a natural staff leader for the program?

STEPS TO IMPLEMENT SAFe IN YOUR HEALTH CARE PROGRAM

- Identify and Engage Key Decision-makers and Stakeholders
- Tips on Planning for Implementing SAFe
- Integrating SAFe with Existing Screening, Diagnostic, and Treatment Services
- Integrate SAFe with Existing Notification and Tracking Systems
- Identify SAFe Service Eligibility Criteria
- Specific Implementation Tasks
- Ongoing Quality Monitoring and Problem-Solving
- Develop Adherence Outcome and Evaluation Procedures

Identify and Engage Key Decision-makers and Stakeholders

- Empower a key individual and group of individuals to assume leadership for implementing SAFe navigation/case management.

- Barriers to implementation are encountered when a key group or individual is either not informed or adequately engaged in the planning and implementation process.

- Key stakeholders include medical directors, clinic directors, and nursing and all staff who provide patient care or who have patient care administrative responsibilities.

Tips on Implementation Planning Strategy

- Designate ongoing leadership and administrative line of supervision for case management.

- Facilitate teambuilding and shared goals for improving services.

- Give particular attention to ways in which SAFe can be flexibly integrated within the existing health delivery system.

- Evaluate structural and operational systems to identify successful and problematic areas.

- Identify needed delivery system changes, particularly in results notification and patient tracking processes, patient education, and use of community resources.

- Designate and clarify relevant staff roles, responsibilities, and expectations.

- Determine patient eligibility criteria for case management services. *(Note: SAFe targets "at-risk" women, i.e., those at risk of delay or non-follow-up. Only a small percentage of women who receive mammograms/Pap smears will be eligible for SAFe services, and only a subset of these women will be in need of intensive SAFe assistance (at Levels 2 or 3). For the relatively small proportion of SAFe clients who have breast/cervical cancer, SAFe services are designed to enhance (not compete with) existing oncology support services where the cancer is being treated.)*

Integrate SAFe with Existing Screening, Diagnostic, and Treatment Services

- Design any necessary modifications to the SAFe Service Protocol to ensure its full integration with your existing organization of care system.

(Note: SAFe can be flexibly integrated into a site to complement and augment existing provider services. Screening, diagnostic and treatment services can be hospital based or "free-standing" (e.g., radiology centers located in the community). Within a hospital, the level of interaction between related services—radiology, surgery, and oncology—can vary a great deal.

The ease of integrating SAFe into existing programs also will vary. For example, if your service system has already implemented programs to coordinate patient services by creating breast centers, women's health centers, or other "one-stop" services, integration of SAFe is generally easier, although it is still important to clearly define SAFe's role in the system and in relation to other related community services. Thus, in some settings, the activities of the CM could be shared, if carefully integrated, with an existing service coordinator or registrar within a radiology center. The advantage here is that the same individual could manage functions such as scheduling appointments, responding to requests for information, and providing case identification of women in need of additional diagnostic tests. In other systems such as in free-standing radiology centers or in hospitals with minimal interaction between screening, diagnostic, and treatment services, SAFe staff could assume a more integrative role with respect to the woman's service needs: they could actively identify and recruit women in need of follow-up services.

SAFe staff must maintain close communication with the parties involved in the screening, diagnosis, and treatment process. Their ability to do so will vary, again depending on provider program structures. For example, in addition to the screening provider, there may be diagnostic/treatment providers (surgeons, oncologists, nurses) at designated follow-up sites.)

- Design your case management plan to be fully integrated with the process of notifying patients of their abnormal screen and with existing patient appointment tracking systems.

(Note: SAFe staff needs to know about all existing notification and tracking systems so that screening and follow-up services are efficiently delivered. While freestanding radiology providers often have limited resources to track patient services, many hospitals maintain computerized data systems that can link screening, diagnostic, and treatment services for each patient. These systems serve a number of functions in addition to storing patient medical data, including "system prompts" to notify patients of their screening and diagnostic appointments and managing data for quality assurance. Patient notification of an abnormal mammogram or Pap smear often consists of a postcard or phone call followed by a certified letter. In some instances, radiologists tell the woman about her abnormal results in person and make their recommendations for follow-up at the same time. Regardless of the method of notification, most providers do not have the resources or staff time to track down non-responders - these women become "lost to follow-up". By working closely with these data tracking systems, SAFe can provide a valuable service in linking women at risk of non-follow-up to their diagnostic and treatment providers.)

✚ Specific Implementation Tasks

- Design any necessary modifications to the SAFe Service Protocol to fit your existing system of care
- Designate Ongoing Leadership of the Program and Administrative Supervision
- Designate or Hire Navigator/Case Manager (See job description, Section VI)
- Implement Organizational Arrangement/Contract for MSW Services (see Section VI)
- Implement Navigation/Case Manager Training
- Implement Necessary System Modifications
- Prepare and disseminate messages about your case management program to all relevant health care providers within your program as well as to appropriate community programs

✚ Plan Ongoing Quality Monitoring and Problem-Solving in Implementation

- Develop and implement ongoing SAFe Quality Management and Data Management Procedures.
- Develop and implement outcome and evaluation procedures.
- Anticipate Staff Turnover.
- Update Training Manual to be consistent with your case management service protocol (Section V).

Optional SAFe MODELS

There are two basic models of SAFe depending on whether the program staff work on-site (at the screening provider's clinic) or off-site. SAFe staff can be located off-site and even at some distance from the screening provider (although they must obviously have information on local resources). For example, the program might be housed in a host hospital social work department, a women's health clinic, community agency or any organization dedicated to breast and cervical care. Whether on- or off-site, the SAFe staff will need a private office or space where sensitive telephone counseling can be conducted.

The On-Site Model

Characteristics of an on-site model of SAFe can vary depending upon provider need and preference, but will typically include the following:

- SAFe staff are working in the same setting (hospital or medical center) as the screening provider;

- Screening, diagnostic, and treatment services are provided at the same site (thus facilitating communication between SAFe and different service providers);

- In addition to telephone-based counseling, there are opportunities for the CMs and the MSW to have face-to-face interaction with SAFe clients;

- SAFe staff can be linked to medical center staff and to provider databases and tracking systems that will give them access to information on diagnostic tests, missed appointments, and other information on SAFe clients.

    For example, an on-site SAFe program could be located in a hospital social work department, work closely with an adjacent radiology screening program as well as with diagnostic and cancer treatment providers in the same medical center, and provide in-person counseling to women who come for their diagnostic tests such as biopsies.

The Off-Site Model

    Characteristics of an off-site model of SAFe can also vary depending upon the host site for the program and how it is linked to the screening provider as well as with diagnostic and treatment providers. The following statements describe how the off-site model is likely to work.

- SAFe services are located at a site separate from the screening provider. Typically, the screening provider is located in a community-based office or mobile unit from which women are referred elsewhere for diagnostic tests. While the off-site SAFe model can be appropriate for many settings, it is especially useful for serving women who live in rural areas and other difficult-to-reach locations.

- SAFe staff provides a client-centered link between several different parties: the screening provider, the hospital or clinic where the woman is sent for further testing, and the oncology department of a hospital (for women in need of cancer treatment). (Note, however, that the primary relationship is with the screening provider and the woman who receives SAFe services.)

- Off-site SAFe staff is primarily linked via telephone to at-risk women. Thus, face-to-face communication is less likely.

- Patient screening and diagnostic information is spread across several sites. Thus, SAFe staff cannot depend on integrated data tracking systems as sources of information on each woman's diagnostic test results, missed or kept appointments, etc. In this case, SAFe staff will depend upon the screening provider and client's reports of the outcome of diagnostic tests and of the woman's follow-up behavior.

- Off-site models of SAFe can assume one of several forms depending upon the location of the various service providers. For example, a SAFe program could be located in a diagnostic and treatment medical center (where social work departments are frequently housed), a community health clinic, a women's health clinic, or a local American Cancer Society office. From this centralized location, the program could serve women from several SAFe screening sites. Typically, the screening provider is located in a community-based office or mobile unit from which women are referred elsewhere for diagnostic tests. While the off-site SAFe model can be appropriate for many settings, it is especially useful for serving women who live in rural areas and other difficult-to-reach locations.

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Promoting better healthcare for women

**THE SCREENING ADHERENCE FOLLOW-UP
(SAFe) PROGRAM**

Patient Navigation/Case Management the SAFe Way

PROGRAM MANUAL

Section V

PROGRAM MANUAL

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> Service Goals
> Staffing
>> Key Characteristics for Service Staff
>> Key Responsibilities
> Options in SAFe

The SAFe Approach to Helping: Empowering Women

> Help is patient-centered and individualized
> Services are culturally sensitive
> Navigation/Case management is based on empowerment practice
> Navigation/Case management is focused, time-limited, and highly structured
> SAFe provides additional services for women with special mental health needs

The SAFe Way Step-by-Step

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>> Three Service Plans
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> **Documenting in the Medical Chart**

Introduction

HOW TO USE THE SERVICE MANUAL

The **SAFe Service Manual** is the guide for case managers who are implementing SAFe case management on a day-to-day basis. It provides step-by-step explanations and instructions for each aspect of the case management service. It is a user-friendly and practical reference tool for the case manager, the clinic staff member who is supervising case management, and the collaborating social worker.

Patient Navigators/Case Managers will find it helpful to read and follow the Manual first during start-up training, in conjunction with the **SAFe Program Training Manual.** You can also consult and review the manual regularly as specific questions and problems arise in providing case management services.

The **Service Manual** spells out information and activities so that case management is done the **SAFe** way:

- Routine and systematic
- Guided by a specific approach and attitude toward helping
- Based on clear roles and responsibilities
- Delivered according to a structured step-by-step procedure
- Accountable through specific record keeping and documentation processes

EXPECTED LEARNING OUTCOMES

In the sections that follow the case manager learns and will be able to:

- Understand the general features of SAFe case management including key program components, program goals, staff characteristics and responsibilities, and program options

- Know and use the central ideas guiding the **SAFe** approach to helping

- Carry out case management the **SAFe** way through specific step-by-step activities and tasks

- Document for service and quality monitoring and improvement using SAFe's forms and tools

What is SAFe Patient Navigation/Case Management?

DESCRIPTION OF SAFe

SAFe is …

- Interpersonal patient-centered navigation/case management. It aims to empower and assist low-income women from diverse cultural backgrounds. These women are known to be at higher risk for non-adherence to diagnostic follow-up and re-screening after an abnormal breast or cervical cancer screen.

- Provided by a bi-cultural, bi-lingual (depending on the demographics of the population served by the site) designated case manager and a collaborating social worker or other mental health specialist.

- Based on the best available evidence for what works.

- A routine part of screening/diagnostic services, so that all women with abnormal screens can be included. The SAFe navigator/case manager reaches out to these women, offering culturally competent communication of information and relevant health education. The navigator/case manager provides supportive counseling to reduce practical, personal, or health system barriers that may interfere with a woman's ability to adhere to what is being recommended for follow-up. The navigator/case manager refers a small number of women with special needs to the collaborating MSW social worker.

- Highly structured. There are clear directions and guidelines for how to provide the navigation/case management at each step. It uses a scripted assessment, health information and supportive counseling initial contact. Decisions about the right navigation/case management plan are simple because they are guided by clear risk criteria. Services are provided for each level of plan according to service protocols.

- Time-limited. Women receive the appropriate level of service for a period of six months to one year or until recommended diagnostic follow-up is completed.

SPECIFIC AIMS OF SAFE

Improve Adherence Behaviors

SAFe reduces barriers to adherence with effective patient-centered services to improve women's follow-up adherence behaviors.

Empower Women to increase health competence

SAFe empowers women to act in their own health-related self-interest now and in the future by increasing their knowledge and coping skills with respect to their medical care.

Provide culturally responsive services

SAFe provides culturally sensitive, and to the degree possible, culturally competent services to reduce culturally influenced social, emotional, and health system or other environmental barriers that may interfere with adherence to follow-up.

Enhance clinic access to community resources

SAFe's case manager researches, identifies, locates and links with key program and resources that help women in a number of ways.

Improve continuity and efficiency of care

SAFe case management is carefully integrated with existing care processes and addresses gaps and difficulties that arise in the care system

Essential Service Components in SAFe

SAFe includes assessment, planning, coordination, community resource linkage, systematic patient tracking, and program evaluation as defined in the Centers for Disease Control and Prevention's case management policy.

SAFe services are in addition to and coordinated with the usual processes of notification of abnormal results, patient scheduling, and follow-up reminders. They should be carefully integrated with these normal procedures.

Key service elements

- Designated clinic staff patient navigator/case management provider

- Fully integrated with system notification of results and patient tracking

- Routine individualized assessment of the full range of risk factors and barriers that are known to contribute to non-adherence

- Assigned navigation/case management service plan for each woman, depending on her assessed level of barriers to adherence

- Patient-centered, individualized health education and supportive counseling by telephone, systems navigation and referral (as needed), and specialized mental health counseling for a small number of women with special needs (mental illness, severe psychosocial distress)

- Tracking patient adherence to follow-up and re-screening, providing reminder calls, and counseling and resource linkage (as needed).

- Providing continuity in patient care as the case manager facilitates a woman's receiving care from different care sites and providers

- Finding, linking and coordinating with community based resources, including sources of funds for treatment and medication, to enhance access

- Implementation, training, service-tracking, and evaluation tools

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STAFFING SAFe

SAFe requires one or more designated case managers who are employees of the host site. The collaborating social worker or other mental health specialist may be contracted in several ways by the clinic/host site. A supervisory clinic staff member with appropriate authority assumes oversight/supervisory responsibility for **SAFe** services.

KEY CHARACTERISTICS FOR SAFe SERVICE STAFF

Patient Navigator/Case Manager

➢ Designated employee of the site and member of the clinic care team
➢ Bi-lingual and bi-cultural (determined by the demographics of the service site)
➢ Good literacy
➢ Excellent communication skills
➢ Personal warmth and charisma
➢ Initiative

Social Worker

➢ Contract or fee-for-service on hourly, as needed basis
➢ MSW or other mental health clinician
  Bi-lingual and bi-cultural if possible

KEY RESPONSIBILITIES FOR SAFE SERVICE STAFF

Case Manager……….

✓ Identifies and contacts eligible patients

✓ By telephone or face-to-face assesses each woman's risks and needs; provides brief health education, supportive counseling and assists with immediate problem-solving

✓ Determines the appropriate on-going case management plan, according to level of risk

✓ Addresses barriers to adherence, monitors clients' progress, provides continuity of care

✓ Refers special needs women to the collaborating MSW for further assessment and help

✓ Locates and coordinates with community resources

✓ Completes tracking and program evaluation data collection forms

✓ Consults with collaborating social worker as needed

Social Worker………..

✓ Contacts patients referred by case manager to conduct clinical diagnostic assessment

✓ Refers and/or provides telephone or face-to-face brief counseling according to protocol to address mental health problems that interfere with adherence

✓ Provides or arranges through an oncology social work department clinical services for women diagnosed with breast/cervical cancer, when indicated.

✓ Consults with case manager concerning difficult patient circumstances

✓ Documents clinical activity according to site specifications

OPTIONS IN SAFE

Providers may choose to modify SAFe navigation/case management in any or all of the following dimensions:

- Target group/eligibility for case management

- Time frame for case management service

- Alternative credentials/background of SAFe service staff

- Approaches to staffing the clinical specialist

- Location and "ownership" of the SAFe service and resulting strategies to integrate the service with the host provider system

Throughout the service manual some of these options and their implications for service are indicated in italics. The Manual for Administrators discusses two models of location and "ownership" of the SAFe service in more detail.

The SAFe Approach to Helping: Empowering Women to Greater Health Competence

GOALS THAT GUIDE SAFE

SAFe's case management is based on theory and extensive research concerning the most effective way to help women who are at high risk for less than optimal adherence to medical diagnostic follow-up. SAFe's approach to helping uses this information about "what works" to achieve specific goals.

Here are the *four* key goals that guide the SAFe approach

1. Help is patient-centered and individualized

This is navigation/case management with and for patients. Services depend on assessing each woman's risks for non-adherence in combination with her actual medical circumstances. Assessment and helping are based on understanding that a patient's non-adherence behavior results from many possible influences. Some of these come from a woman herself and some come from the health care system and wider social environment. Often both influence the behavior. For example, a woman may be feeling she is still "on probation" at a job and find that available clinic appointments are at times she sees as impossible to take off work. Also, cultural differences play an important part in the way a patient understands and deals with her health problem, as well as the way she understands and relates to the health care system and the way it relates to her.
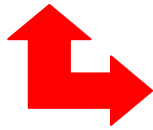
2. SAFe services are provided in a culturally appropriate and sensitive manner, using bi-lingual, and/or bi-cultural personnel to the extent possible.

The case manager is trained to facilitate fuller and more open communication between a woman and her health care providers, whether because of language barriers or culturally mediated differences in understanding, beliefs and preferences.

3.   SAFe case management is based on empowerment practice

This means giving women the tools to promote overall health competence. These tools include information, emotional support, and guidance/coaching in effective communication and problem solving. Greater health competence mean that patients can…

- Be more knowledgeable partners in their health care
- Be more self-confident in dealing with health care systems and providers
- Make health-related decisions in their own best self-interest now and over time.

4.   Patient Navigation/Case Management is focused, time-limited, and highly structured

SAFe's navigation/case management services are designed to be efficient and cost-conscious. Case management helps women keep their medical appointments by addressing immediate problems and barriers to adherence. Services end at a pre-determined point, usually once diagnostic resolution and/or re-screening is achieved. Clinical services are guided by scripts and protocols to guarantee that they are provided in a consistent and effective manner.

The **SAFe Training Manual** discusses and explains these goals in greater depth. Skills and specific techniques to illustrate and support goal achievement in SAFe case management practice are provided.

5.   SAFe Case Management provides additional services for women with special mental health needs

SAFe's navigation/case management is designed to recognize and help with patients' mental health problems. There is evidence that significant psychological distress can contribute to women's non-adherence to follow-up. Thus screening, assessment, and referral/brief counseling for mental health are systematically and routinely provided. Recently, the US Task Force on Prevention recommendations highlighted the opportunity for care improvement through the routine inclusion of depression screening in primary care. This is particularly the case for the medically under-served women who are the target population for SAFe case management. These women are known to more often lack a regular source of medical care, to be less likely to have their mental health problems recognized, and to have less access to specialty mental health treatment. SAFe includes a short and effective mental health screening questionnaire in the initial assessment. Women with high screening scores for depression and/or anxiety are referred to the

MSW for clinical assessment, referral and, when necessary, brief, problem-solving treatment. The SAFe case manager identifies and establishes links with mental health resources, so symptomatic women can be referred for treatment. In some communities there are appropriate specialty resources available and accessible. When there are not, the SAFe MSW becomes an important short-term treatment resource.

The SAFe Way Step-by-Step

STEP ONE: IDENTIFYING AND REACHING ELIGIBLE WOMEN

Who is eligible for SAFe services?

Women with **abnormal screening mammograms** or **PAP smears** who are at high risk for non-adherence are the target population for **SAFe**. Specific eligibility criteria for **SAFe** can be determined by each provider in response to local circumstances. Keeping in mind that **SAFe** is designed to target low-income women, minority women, and other medically under-served women, suggested eligibility criteria are the following:

- ❑ **40 years and older (mammogram)/ 18 years and older (PAP)**

- ❑ **Income at 250% of poverty level or less**

- ❑ **Index mammogram with ACR designation of 3, 4, 5 or 6; Abnormal CBE findings**

- ❑ **Index pap showing moderate or severe dysplasia (ASCUS, HGSL or LGSL) or carcinoma in situ**

*One optional approach in **SAFe** is to provide the initial brief assessment and educational intervention to **all women who are screened**. This approach may improve the ability to locate and contact women who subsequently have abnormal screens and need follow-up. It also can improve regular re-screening for women with normal screens.*

*Another option is to provide **SAFe** service only to those **women who fail an initial appointment** following an abnormal index screen.*

Identifying eligible women – linked to notification of abnormal result

The case manager regularly identifies all eligible women once the best processes and procedures to accomplish this in the site have been worked out with the **SAFe** supervisor.
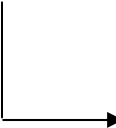
Based on experience it is highly recommended that SAFe identification, first contact, and the initial assessment/health education be integral to the site's process for notification of abnormal results. The case manager calls or meets personally with a woman to provide information about an abnormal screen and also does the systematic need/barriers assessment and initial health education and problem-solving intervention. If the clinic physician or nurse provides the results, that clinician could immediately ask the woman to speak with the SAFe case manager. This provides an opportunity to provide education so that a woman understands the importance of what she is being told.

Effective **SAFe case management** requires systematic and routine identification of eligible women. It is important for all eligible women to be identified as soon after an

abnormal screening result as possible. Accomplishing this can be problematic, especially when the **SAFe** case manager is in a different location/provider site than where the initial screening takes place. Experience has shown that the **SAFe** supervisor needs to set up, and the case manager carry out, careful procedures in cooperation with site personnel to identify women, and not just rely on referrals.

Determining the usual service pathway and timeline from CBE/index mammogram or PAP smear, to notification of results, to diagnostic procedures and diagnostic resolution to regular re-screening is the first task in **SAFe** case management. These processes and timelines will vary from setting to setting and can be quite complex, especially if different providers are involved along the way. For **SAFe's** intervention to be provided in a time-sensitive way, considerable attention needs to be paid to integrating identifying eligible women with a site's clinical care processes, particularly notification of abnormal results.
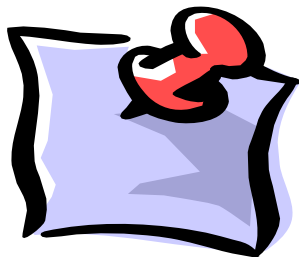
Contacting eligible women and outreach

Research from other programs as well as **SAFe** shows that **SAFe's** target population can be difficult to locate and hard to follow over time. Women may move frequently, change telephone numbers, or be without a telephone. They often live with relatives or employers who may not pass on messages, or a woman may be reluctant or unable to provide that telephone number. They may self-protectively screen telephone calls from unknown persons using caller ID. In previous experience **SAFe** repeatedly encountered a significant problem with reaching eligible women. A small percentage (5-10%) turned down the service when reached. A larger percentage of women were never reached, and these "failed-to-locate" woman tended to adhere at a lower rate than did women who were receiving **SAFe** services. Thus a **SAFe** program needs to give considerable attention to designing identification and outreach approaches in order to assist the maximum number of high-risk women.

When screening and diagnostic services are combined the case manager may be able to meet with a woman in person the same day she has her abnormal screen. The patient may receive diagnostic services that same day as well. This is likely to be the most effective approach when it is feasible. Experience shows that a personal meeting and a beginning relationship with the case manager will make a difference when she tries to call the woman later.
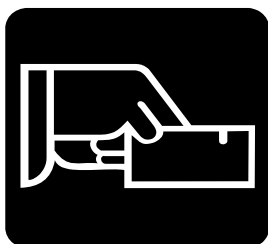
If the case manager is a staff member of the screening site, it may be feasible to provide the brief initial needs assessment to all women screened. The case manager could introduce herself and provide a card, letting a woman know that she will be in touch in the event there is any follow-up needed. Again, the importance of integrating case management with the results notification process is likely to be the most effective way to reach women in a timely manner.
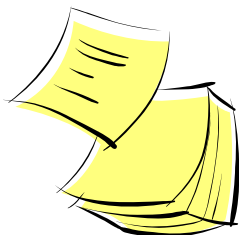
Outreach Strategies

When multiple screening sites are involved, make efforts to alert all women coming for screening that the **SAFe** services exist. In many cases **SAFe's** initial contact with a woman will be by telephone after she has left the screening site. It will help if the woman already is a little bit familiar with **SAFe**. **Posters** about the program can be placed in prominent locations. **Flyers** about the program should be made available in screening sites. Asking the screening site receptionist to give each woman a flyer as she checks in is an effective approach.

Have **cards** with the case manager's name and phone number available in screening sites. Who is the person in the site with most contact with the women? Can that person **hand out cards** and suggest that if the woman would like additional service/help related to her health care she can call the case manager.

Have **SAFe "stick-it" notes** made and put one on the medical chart of a woman with abnormal results as a reminder to the physician and nurse to mention that the service exists.

Are there other community resources likely to be used/trusted by the target women for your site? Would flyers or cards help reach women who might have gone for screening already. In many communities there are existing **outreach programs** that are successfully getting women in for screening. The idea would be to link with this effort to also emphasize the importance of follow-up and the existence of some support services to help with this.

Direct community outreach may be successful. [UCSF program] describe briefly.

How many attempts to contact?

Frequently the initial effort to contact a woman eligible for case management may be by telephone. Because **SAFe** is an outreach service, the case manager needs to be prepared to make a substantial effort to reach a woman initially. Up to five attempts to call should be made, including calls made in the evening, after normal working hours. When

telephone contact is unsuccessful, the case manager can send a letter explaining the **SAFe** service briefly and asking the woman to call a designated number. In the case that a woman has no phone, outreach will have to be done by mail. Keep in mind that the case management service is voluntary and a woman can always make the decision not to participate. However, if she is never reached, she cannot make that choice. **When SAFe case management is combined with notification of abnormal results, the necessary effort and time to reach women is more efficiently allocated.**
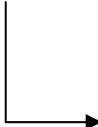
In telephone contact there are several important points to bear in mind:

➕   **Remember the patient's right to confidentiality**. Speak only to the woman herself. The reason for your call and the information you have to discuss is personal and confidential. When someone answers the telephone identify yourself by name and the screening site you represent. Ask for the woman by name. If she is not there, ask when she might be home so that you can call back, or leave your name and telephone number and ask that she call you. Do not leave a message other than your name and number.

➕   **When the woman has not yet been notified of her results**. If navigation/case management is not meshed with abnormal results notification, then at the time of the initial contact it is possible that a woman states she has not been notified, or seems not to know about the results. In this case the case manager refers her back to the appropriate person to get this information before doing anything else, and calls her back at a later point. The case manager should also attempt to facilitate getting this important information to the patient.

STEP TWO: THE INITIAL CONTACT -- HEALTH EDUCATION, SUPPORT, AND RISK ASSESSMENT

After successfully contacting a patient, whether face-to-face or on the telephone, the navigator/case manager provides the initial **health education, support, and risk assessment**, using the **SAFe** initial contact script.
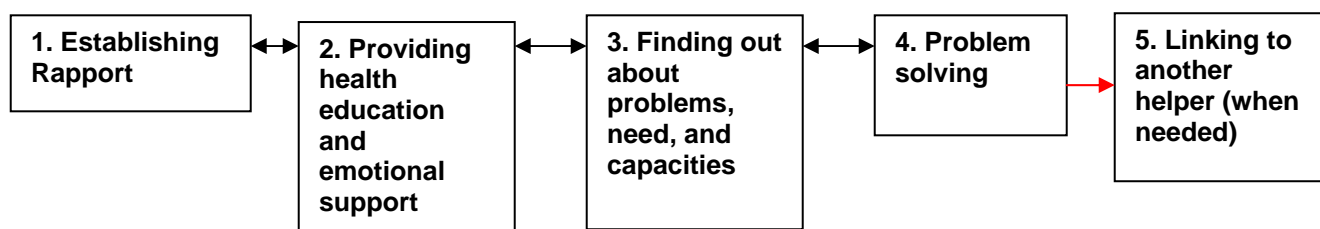
This section describes the **purpose, structure, and specific content** of the initial contact, which may be in person or over the telephone. Refer to the initial case management assessment/intervention form (there is one for mammography and one for PAP) in Section VII of the Tool Kit to see how and where it relates to each of the tasks described below.

Once the woman has agreed to receive the service you are ready to begin the initial assessment, education, and counseling contact. This is the heart of the **SAFe** service. In this initial contact with a woman you are accomplishing a number of **key tasks**. You use the **SAFe** form to guide you through this first contact. The form and its prompts assure that the same questions about risk are asked for each woman. It also means that the health education information is provided in an accurate and consistent manner. By holding closely to focus, it emphasizes that **SAFe's** support and assistance are offered from an empowerment perspective that maximizes a woman's efforts to follow-up through on her own health care needs concerning this specific problem.

However, no standard form can exactly match or anticipate each woman's circumstances at the time you first speak with her.   In certain cases you will need to leave a question or piece of information out because it is not relevant. Or you may have to add questions to clarify a situation.

Key Tasks of the First Contact

In this initial contact with a woman you are accomplishing a number of key tasks. Each is discussed in more detail below.

| 1. Establishing Rapport | ↔ | 2. Providing health education and emotional support | ↔ | 3. Finding out about problems, need, and capacities | ↔ | 4. Problem solving | → | 5. Linking to another helper (when needed) |

1. Establishing Rapport. SAFe is interpersonal helping. It requires a "good-enough" level of trusting relationship between the client and the helper. This level must be established in the first contact. This requires skill and sensitivity and cannot be put into a script. Skills for and practice in establishing rapport in the first contact are dealt with in the Training Manual.

🔲 An important aspect of establishing rapport is providing services in a culturally competent and appropriate manner. Speaking the language in which the woman is most comfortable is a start. Also important is to become familiar enough with the initial prompted form so that you can use it, but speak with a woman in a natural, comfortable, and empathic way that leaves room for you to listen and respond to her as well.

2. Health Education and Emotional Support. Many of the questions and exchanges in the initial contact focus on providing information about the specific follow-up tests and/or procedures that the woman's doctor has recommended.   You are also checking for evidence of misinformation or misunderstanding that the woman may have. Finally, you are providing support and affirmation for the importance of her own health and well-being. The **Training Manual** provides more detailed information about screening results and diagnostic procedures, so that you will be familiar with the health care issues

you are discussing.

3. Finding out about problems and needs: Many questions on the initial form are to let you learn about specific circumstances that could interfere with a woman following recommendations. The form assists you in conducting a systematic **assessment** of risk factors for each woman. It asks questions about all of the different factors that are known to contribute to problems with adherence, including finances, access to medical care, problems with the provider site and/or staff, family stresses, significant worries or concerns, and mental illness. It is important to follow the form and its prompts closely so that each woman is assessed comprehensively and receives the same service. But the interview also needs to be a genuine and natural exchange, not just a rote exercise. It also needs to be an opportunity to learn about and respond with empathy to the true feelings and circumstances of each woman, no matter how unique or unusual. The case manager's skill and judgment are critical to making the call effective, namely, getting all needed information without taking too long or irritating a woman by making her feel "grilled."

4. Problem-solving. Some barriers and problems a woman identifies can be addressed in the first contact/telephone call, and most women can and should take responsibility for actively solving them to the fullest extent possible. It is important to understand SAFe's approach to case management as a service that provides only the amount of help a woman actually needs. It is costly and demeaning to a woman to do things for her that she can do for herself entirely, or with some encouragement and suggestions from you. However, women do face situations that they cannot deal with alone. Women also vary in terms of how effective they feel (no matter how it may seem to you) about solving a problem.

Here are some important points about problem solving…

> Keep in mind that a problem that seems simple to solve to you may not seem that way to the woman you are talking to. Thus a part of what you are deciding in the first interview is not just how difficult or numerous the problems identified are, but, no matter what the problem, how confident and capable to handle it does the woman see herself?

> Notice on the form that after a woman identifies a concern or problem in response to your question, you then ask her if she has thought of some ways she could solve it. In asking this you are finding out how effective she seems to you and how effective she seems to see herself to be with respect to that particular situation. All of your problem-solving efforts, both in the initial contact and in any other services you undertake, should be in line with your sense of what the individual woman (and remember how different people can be) can do for herself.

> The women SAFe serves may have extensive and long-term environmental and resource deficits and/or chronic family and personal problems. It is important for you to establish clear boundaries for assistance in the first contact/telephone call. It is not helpful or ethical to elicit or encourage information-sharing of a detailed and extensive nature about problems that, realistically, SAFe is not intended to address. You can provide information about resources for any problem to a woman, but should confine problem-solving efforts to those circumstances that seem to directly influence the likelihood of a woman's

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adherence.

🞦 Identified problems or needs that can be addressed by the woman herself once she has considered ideas with you, or by either the woman or you calling a resource, should be considered dealt with in the first contact. Problems that require more extensive effort on the case manager's or MSW clinician's part will mean assigning a woman to a more intensive level of service, as discussed in Step Three, below.

5. Linking to another helper. Some of the problems a woman may have, for example significant emotional distress or depression, indicate the need for a referral to the MSW social worker. There are some things you can do to make it more likely that a woman will agree to talk with the social worker.

It is normal for people to have mixed feelings about asking for and accepting help. You can expect to hear from some women hesitation, uncertainty, or even refusal at first when you ask about having the social worker call her. You do not want to insist or force a woman to say yes. **However, when you hear doubt or negative thoughts you do not have to accept this as the final answer. You can…**

Ask is there some concern about having the social worker call that she would like to share, giving you a chance to reassure or explain the service
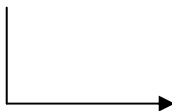
Let her know that many people hesitate to talk to someone they don't know, but that they find it helpful once they give it a try

Help the woman with other needs while building a stronger and more trusting relationship and then ask her again to agree to have the social worker contact her

STEP THREE: DETERMINING THE SERVICE PLAN

After completing the initial contact the case manager has the necessary assessment information to determine the appropriate service plan.

🞦 SAFe offers three service plans for tracking, supportive counseling and systems navigation to improve adherence. It is not a "one size fits all" program. After completing the initial assessment and counseling contact the case manager has the information needed to determine the appropriate plan of service. The completed initial contact form serves to document the case management plan. On it the case manager indicates the results of the needs/barriers assessment, the appropriate service level, and the planned actions.

Some women will need only one or two reminder calls with some health education reinforcement after the initial contact. Other women will have more extensive practical and environmental problems requiring systems navigation and problem solving after the initial contact. A few women will be emotionally distressed or experiencing serious family problems requiring short-term professional clinical intervention from the MSW social worker; these are women with special needs.

The three levels of service in SAFe are designated Level I, Level II, and Level III. Each level has standard service activities that form the plan. Service level is based on tested criteria for an objective and consistent assignment. Using the criteria and the information from the first telephone call or contact, the case manager should usually be clear about the appropriate service level. In cases that are uncertain, the case manager consults with the SAFe social worker.

Criteria for Service Plan Levels

Service Level I

All of the following criteria must be met.

- No service or system barriers to follow-up
- Adequate or good psychological health
- Some understanding of reasons for and why tests are important
- Answers yes to these questions
    Do you have a regular doctor?
    Do you have an appointment for a next exam?

Service Level II

Any one of the following criteria must be met.

- Systems navigation or service referral needed
- Mild psychological distress (PHQ Score 5-9)
- Significant co-existing health problems
- Poor understanding of reasons for follow-up plus answers no to one or more of these questions:
    Do you have a regular doctor?
    Do you intend to keep your appointment (if yes to having one)?

Service Level III

Any one of the following criteria must be met.

- High psychological distress ()
- Significant worries or concerns
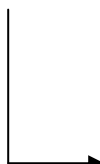- Highest severity of screen or referral for cancer treatment

Basic or enhanced patient navigation/case management?

SAFe's basic case management services, including systematic assessment, health education and emotional support, identifying and linking with community resources, tracking and reminders can be provided by the designated case manager. Experience with SAFe has shown that this will adequately meet the need of up to 80% of the women. SAFe is an enhanced case management approach designed to meet the needs of all targeted women, including those with serious mental health problems. Experience has also shown that contracting for carefully defined MSW or other mental health professional services is a reasonable value-added cost. However, some provider sites may opt for, or find feasible, basic case management only (Level I and II Service). SAFe provides a basic case management approach even when Level III services are not provided.

If a provider elects not to provide clinical specialist services (Level III) the following modifications are recommended:

- *The case manager should refer to specialized mental health services any woman meeting mental health screening criteria and put a note in the woman's medical chart about her mental illness symptoms.*

- *The case manager should be familiar with special resources for women with cancer such as support groups, American Cancer Society materials and help, and should refer women to the hospital oncology social work department where they are being/will be treated for assessment of any additional need.*

STEP FOUR: ON-GOING SERVICE

On-going basic service is provided by the case manager, supplemented by the psychosocial/mental health clinical specialist for the small number of women with special needs. The case manager tracks appointments, problem-solves as needed, and locates and coordinates with needed community resources.

Time-frame for Patient navigation/case management Services

How long should a woman receive case management services? This question needs to be answered by the provider site and determines the timing and extent of SAFe's on-going services. The SAFe model as described provides services for 6 months to one year.

> ***Provider systems can elect to provide SAFe case management in different time frames. What matters is maintaining the key service elements outlined earlier. Case management might focus on the first month after the abnormal result and then re-contact a woman only if she misses an appointment, or for a routine "booster" message about re-screening a year later. This is basically what is provided in SAFe Level I service. Or, case management services could be available until a woman achieves diagnostic resolution or achieves a normal index screen. In the case of cervical screening this can be as long as three years.***

Whatever time frame is chosen, the elements for SAFe's on-going case management service are described below.

Tracking appointments

SAFe's help is carefully focused, and timed to help a woman get the medical care she needs. It is critical that services are coordinated with the woman's scheduled follow-up tests and procedures. This is to provide timely reminders and problem solving if barriers arise, including missed appointments. Case management requires a feedback/tracking system concerning each woman's scheduling of and compliance with appointments. In some sites this information will be available in a computerized patient tracking database. In other settings the SAFe case manager may need to retrieve information by hand from patient records and clinic appointment records. Careful integration of case management and appointments processes pays off in greater efficiency in use of the case manager' s time.

> **If the SAFe service is located in a screening site and diagnostic work is performed in a different site, memoranda of understanding and information-sharing procedures will need to be worked out to assure that timely and accurate patient tracking information is available.**

Three Service Plans

Service Plan for Level I

The plan for Level I is to provide routine case management. It is typically the appropriate service plan for about 50% of women. Level I intervention consists of the following **in addition to the initial assessment and health education/supportive counseling intervention that has been described above.**

✛   Follow-up telephone call prior to the woman's next scheduled recommended follow-up procedure(s) to

- ✓ remind her of the appointment(s)
- ✓ emphasize the importance to her health of adhering
- ✓ ask if anything has come up that may make it difficult for her to follow-through with recommendations

✛   Check-back call to the screening/diagnostic site to determine whether the appointment(s) was kept.

✛   End of service call reinforcing the health competence message with respect to regular re-screening.

Service Plan for Level II

Level II intervention is designed to assist women who have significant environmental and resource problems that interfere with adherence and require some support and help from the case manager. Women in Level II receive help in systems navigation and referral.

Level II intervention consists of the following **in addition to the initial assessment and education/supportive counseling intervention that has been described above.**

- Follow-up and check-back telephone call prior to scheduled procedures (as in Level I.

- **Systems navigation**, including referral to community resources, for specific barriers to follow-up and/or **empowerment interventions** to increase a woman's health competence.

- End of service call as in Level I

Note: Systems navigation and empowerment interventions are discussed more fully in the **Training Manual**.

Service Plan for Level III

At this service level the clinical social worker provides the following:

- Additional brief **clinical assessment for depression and anxiety**

- When diagnostically indicated, **mental health services** according to the protocol described in the **Training Manual – Clinical Specialist Supplement**

- For women with **cancer diagnosis** and no mental health problem, referral to oncology social work and/or cancer support group if there is an assessed need or a woman requests this

- Brief clinical counseling and follow-up for women with other emotional and family stresses

- A woman who receives Level III services also receives Level I supportive follow-up calls from the case manager, and, if indicated, receives systems navigation help from the case manager (Level II) for identified environmental barriers.
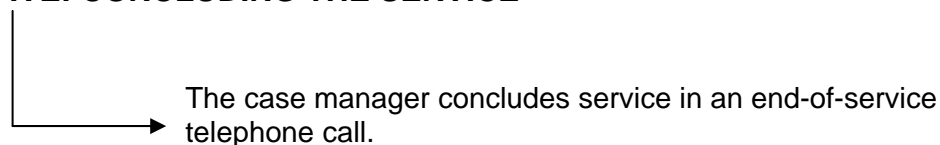
Note: Further information and a more detailed discussion of the SAFe mental health intervention and other Level III services is provided in the **Training Manual – Clinical Specialist Supplement.**

Linking to Community Resources

SAFe navigation/case management enhances access to needed resources for all women served at the provider site. It is the case manager's responsibility to research, identify, locate and link with key programs that assist women in a variety of ways. In developing and updating this resource bank and eligibility criteria the case manager readily knows what is available to meet the needs identified for an individual woman. What these resources are will depend on the state and location of the provider site. In general, they

include transportation, emergency assistance, brief child care, cancer support groups, out-patient mental health, help with bill payment, programs that help pay for medical care and medications, legal assistance, drug and alcohol counseling as among the most essential. The case manager makes a particular effort to locate and link with both formal and informal culturally-targeted resources.

STEP FIVE: CONCLUDING THE SERVICE

The case manager concludes service in an end-of-service telephone call.

⊹ SAFe routinely concludes services when the program's period of service is over. A woman may request termination of services at any point as well. Also, services may be concluded when a woman can no longer be located after repeated efforts, or if she repeatedly fails to keep scheduled appointments.

⊹ SAFe is a program that depends on a trusting helping relationship between a woman and the SAFe case manager, and it is important to end the service in a professional and systematic manner. This involves the following activities during the last telephone call:

- Clearly telling a woman that the service is ending and when it will end
- Briefly reviewing the accomplishments of the service and acknowledging any difficulties
- Reinforcing self-health care, including regular re-screening
- Linking a woman with other helping sources if appropriate and not already done

Non-adherence to follow-up and/or treatment

In this category are woman who can be reached or who call to speak with the case manager, but who do not keep appointments in spite of efforts that are made to address identified barriers. SAFe is designed to help but not to harass a woman. This is an important distinction, requiring thought and clinical judgment.   It is recommended that the case manager and MSW confer and, if appropriate, seek additional consultation for such a woman to devise an individualized approach. It is recommended that the case manager refer a woman to the MSW **before** the woman misses three scheduled appointments for follow-up and is terminated from further services with the provider site. It is expected that there will be very few women who present in this way. The case manager may consider a home visit for a non-adherent woman who continues to be positively engaged with the case manager and/or the MSW before determining to end the SAFe service.

Documenting in SAFe

INFORMATION AND CONFIDENTIALITY

Assuring confidentiality is a critical concern in providing service and collecting and managing information about clients.

SAFe's service staff must responsibly ensure the fundamental right of every woman to confidentiality of her conversations with you and in the records you maintain, and privacy concerning the information she reveals at any point. SAFe staff have an ethical obligation to safeguard this right through careful practices, including the following:

- Never discuss a woman's circumstances except with SAFe personnel for purposes of clarification and supervision, or with authorized health professionals who are treating her at the screening or diagnostic sites.
- Keep all records and forms in a locked drawer except when you are using them. Do not leave forms or records on top of your desk or in any location where others can view them.
- Do not share details of a woman's circumstances with other professionals or agencies before you have her verbal permission to do so.

SAFE SERVICE AND QUALITY MONITORING FORMS

DOCUMENTING IN THE PATIENT'S CHART

The case manager should note in the patient's medical record circumstances directly bearing on a woman's ability to adhere to recommendations. Examples of such circumstances are the following:

- ✓ Significant mental health problem (noting the patient's PHQ score, if 10 or greater)
- ✓ A woman expressing suicidal thoughts or ideas (also notify the clinic administrator at the time)
- ✓ A health system barrier that the case manager is unable to resolve

Other information that could be useful to clinic providers might need to be included in the medical record, and the case manager should consult with the SAFe clinic supervisor to determine whether or not it would be appropriate.

SAFe Tool Kit: Chapter 6

SAFe QUALITY MONITORING and OUTCOME EVALUATION

Chapter 6 outlines key patient navigation/case management monitoring and evaluation processes.

✚ **SAFe navigation/case management process monitoring objectives**

- Identify all eligible women from the screening provider(s) in a timely manner
- Locate women to assess for needs/barriers and offer initial case management service
- Identify health system barriers to adherence

✚ **SAFe navigation/case management outcome evaluation**

- Achieve timely adherence to diagnostic follow-up
- Achieve timely rescreening
- Patient personal barriers to adherence resolved
- System of care barriers to adherence resolved
- Patient satisfaction with navigation/case management services

✚ **SAFE CASE MANAGEMENT PROCESS MONITORING**
Key Process Objective: Identify all eligible women from the screening provider(s) in a timely manner.

Quality Indicators:
- Protocols and processes exist to assure integration/communication of case management function with reporting of screening results and informing women of abnormal screen.
- Number of days passed between date of patient initial screen and first attempt to contact her by the case manager (monitor monthly)

- Number of women who are contacted by the case manager compared to the number reported by screening provider(s) to have abnormal screens (check semi-annually)

Key Process Objective: Locate women to assess for needs/barriers and offer initial patient navigation/case management service.

Quality Indicator:
- Number of women successfully reached/located and accepting case management compared to the number of women identified as eligible (monitor bi-monthly)

Key Process Objective: Identify health system barriers to adherence

Quality Indicators:
- Reporting feedback loop from case manager to provider management exists
- Health system uses information from case management in formal quality improvement plan

SAFE NAVIGATION/CASE MANAGEMENT OUTCOME EVALUATION

Key Patient Outcome: Achieve timely adherence to diagnostic follow-up

Quality Indicator:
- Percentage of women receiving case management services who are adherent to recommended diagnostic testing within a designated time frame compared to the site specific baseline adherence rate prior to initiation of SAFe case management

Key Patient Outcome: Achieve timely rescreening

Quality Indicator:
- Percent of women who rescreen (within 12-18 months) compared to the site specific baseline percentage prior to the initiation of SAFe case management.

Key Patient Outcome: Patient personal barriers to adherence resolved

Quality Indicator:
- Prevalence rate of problems identified at initial assessment compared with reported percentage of problems resolved on service forms (monitor aggregated data bi-monthly)

Key Patient Outcome: Patient satisfaction with SAFe services

Quality Indicator:
- Level of women's satisfaction with SAFe (administer Satisfaction Survey at conclusion of service period; monitor aggregated data semi-annually)

Key System of Care Outcome: Organization of care barriers to adherence resolved

Quality Indicator:
- Planned system changes are in place and working effectively

THE SCREENING ADHERENCE FOLLOW-UP (SAFe) PROGRAM:

Patient Navigation/Case Management the SAFe Way

TRAINING MANUAL

Contents

Overview

PURPOSE AND GOALS

The training manual prepares the case manager to begin SAFe case management. Supplemental training material prepares and guides the MSW in helping women with special needs. The manual provides background information, discussion topics, skills review, role-play vignettes, and supplemental resources to direct and support the training process. The training manual is organized to achieve **six training objectives**:

1. Increase knowledge about
   - Breast and cervical cancer
   - Screening services
   - Follow-up tests and procedures for abnormal mammograms and Pap smears

2. Increase understanding of
   - Risk factors for poor adherence following abnormal screens
   - Needs of high-risk women
   - Why women may not adhere

3. Increase cultural sensitivity and competence

4. Learn basic ways to empower women and increase their health competence

5. Review and enhance basic interviewing, counseling, and resource linkage skills

6. Increase knowledge of typical system barriers and service obstacles and resources available

HOW TO USE THE MANUAL

The designated case manager and MSW should read the manual before holding the formal training session, and then use it to follow along with the training session. The manual also serves as a handy reference while doing on-going case management. The manual is used together with the **SAFe Service Manual**, which provides the specific information about how to help using SAFe case management. There are pre and post-tests included in the appendix at the back of the manual. It is a good idea to take the pre-test before you read the manual and begin the training. Then, after completing the training, take the post-test. When questions are missed you can go back and review sections covering that information.

TRAINING INSTRUCTIONS

In previous implementations of SAFe the training for direct service personnel (case manager and MSW) has required approximately 6-8 hours or 1½ days. The material covered in the training manual can be broken into two general sections: 1) background information about cancer, screening, diagnostic procedures, women at risk for non-adherence and known risk factors and barriers; and 2) knowledge, skills and attitudes for effective case management helping in SAFe.

No matter how familiar designated SAFe staff may believe themselves to be with the information about screening and diagnosis, it is important to take sufficient time to review this material and allow for questions and clarification. We recommend using a nurse or other clinician to present

and explain this content. There are useful videos available as well. In addition to the clinical information, SAFe staff need to understand in detail the specific pathways (who does what, when, where?) followed by the patient from initial screen to diagnostic resolution.

The remainder of the training focuses on the nuts and bolts of effective implementation of SAFe case management. Included in the manual are discussion points with questions to consider, and opportunities to stop and role-play for better mastery. For this second training component a purely didactic presentation and approach is not enough.

The SAFe MSW should complete the entire training with the case manager. In addition there is a supplemental "Clinical Specialist" training module for this clinician.

Cancer, Screening, Diagnosis and Treatment

BREAST AND CERVICAL CANCER

Background

Breast and cervical cancer are widespread health problems in America.   Here are some facts and figures.

Breast Cancer

Breast cancer is the most common cancer among women (excluding cancers of the skin).

- Breast cancer is the leading cause of death for American women aged forty to fifty-five. Among Hispanic and African American women, breast cancer is the most commonly diagnosed cancer. Breast cancer among Asian American/Pacific Islander is less common than among white and African American women.

- Some 192,200 women will discover that they have invasive breast cancer this year, and another 47,100 will have *in situ* breast cancer (meaning the cancer has not yet spread into the surrounding tissue).

- Among Hispanics, 8,600 women developed breast cancer in 2001 and among African Americans, 19,300 women. The number of Asian American/Pacific Islander women diagnosed with breast cancer is less than other racial/ethnic groups. However between 1990 to1997, the number of Asian American/Pacific Islander women diagnosed with breast cancer has increased dramatically.

- In 2001, 40,200 women were expected to die from breast cancer. Among Hispanic women, 1,800 deaths occurred in 2001. Among African American women, 5,800 deaths from breast cancer occurred in 2001.   Breast cancer is the leading cause of death among Filipino women in the U.S.

Importance of Screening and Early Detection: Early detection and treatment of breast cancer could save lives.   Detecting breast cancer at an early stage before it has spread to other areas of the body is the key to decreasing the death rates and improving survival.

- Among Hispanic women, lower rates of screening tests such as mammography has been thought to contribute to a later diagnosis affecting prognosis and survival.

- Among African American women, a diagnosis at later stages may contribute to the higher death rates among this group.

- Asian American/Pacific Islander women are the least likely group of women to have ever had a mammogram.

Cervical Cancer

Cervical cancer is one of the leading causes of cancer-related deaths in women in the United States, yet it one of the most successfully treatable cancers.   Here are some facts and figures:

- Some 12,900 women discovered that they have invasive cervical cancer in 2001 and about 52,000 carcinoma *in situ*.

- Most cervical cancers occur in women between 35 and 55 years of age.

- Rates of invasive cervical cancer are increasing in women under the age of fifty.

- Vietnamese women age 30 to 54 years old are more likely to be diagnosed with cervical cancer followed by Hispanic and African American women. Chinese women tend to have the lowest rate.

- Cervical cancer was the cause of death for 4,400 American women in 2001. The death rate among African Americans is 6.7 per 100,000 women in comparison to 2.5 per 100,000 white women. The high death rate is due to the high number of cervical cancer deaths among older African-American women.

- The survival rate for women with localized cervical cancer is 92% at 5 years. This high survival rate highlights the importance of screening and early detection.

Importance of Screening and Early Detection: **Early detection and treatment of cervical cancer saves lives.**

- If all women had pelvic exams and Pap tests regularly, most pre-cancerous conditions would be detected and treated before cancer develops. That way, most invasive cancers could be prevented. Any invasive cancer that does occur would likely to be found at an early, curable stage.

- The populations who tend not to have Pap tests include older women, the uninsured, ethnic minorities, especially Hispanics, elderly African American women and poor women, particularly those in rural communities.

Detecting breast and cervical cancer at an early stage before it has spread is the key to improved survival and decreased mortality rates.

<u>**What we know about causes of cancer**</u>

Breast cancer. Some of the risk factors that increase the chance of getting breast cancer are known. However, we do not know yet what causes most breast cancer. While scientists are making headway in understanding the process of chemical change in the cells that leads to breast cancer, they do not know what leads to these cell changes.

Many risk factors for breast cancer have been identified. Some can be changed and some cannot. Having risk factors does not lead to cancer. Some women with one or more factors never get the disease and others with no risk factors do. It is important to understand that even when risk factors are present when a woman has breast cancer, there is no way presently to prove that it caused the cancer. Current research supports the following risk factors: gender (being a woman); age (risk increases as you get older); certain identified genes (about 10% of cases of breast cancer); family history of breast cancer; menstrual history (early onset or late ending); not having children; oral contraceptive use; long-term use of hormone replacement therapy, breast feeding (decreases risk);

and some evidence for the life-style factors of alcohol consumption, obesity, and physical inactivity. (See the American Cancer Society web site **www.cancer.org** for a more detailed discussion of this information.)

Cervical cancer. Most cervical cancers (85-90%) are of the squamous cell variety. The generally supposed cause of almost all of these cancers is the sexual transmission of the human papilloma virus (HPV). Thus risk factors for squamous cell tumors are similar to those of other sexually transmitted diseases. These factors include early age at first intercourse, multiple sexual partners, low socioeconomic status, and a history of a sexually transmitted disease.

However, HPV infection does not completely explain this type of cervical cancer. Most women with HPV don't get cervical cancer, and some women get cancer without having HPV infection.

Adenocarcinoma of the cervix is a much rarer form of cervical cancer. Sexual transmission of the HPV virus does not play a major role in the development of this variety of cancer, and the risk factors are largely unknown (See web site, as above).

Human Papillomarviruses (HPV)

Human Papillomarviruses (HPV) are a group of more than 100 types of viruses. They are called papillomarviruses because certain types of viruses may cause warts or papillomas, which are benign tumors. The HPV viruses that cause common warts grown on hands, feet are different from the HPV viruses that cause the growth of warts in the mouth and genital area. Genital warts, or <u>condylomata acuminatum</u> are related HPV types, 6 and 11. These warts may appear within weeks after sexual contact with a person with HPV, or it may take months or years or it may never appear.   HPV infections often do not cause any symptoms.

HPV Infection and Cancer Risk. HPV is now recognized as a major cause of cervical cancer. As a sexually transmitted virus, HPV is classified into two categories, "low risk" and "high risk".   Low risk and high risk HPV types can lead to the growth of abnormal cells that may ultimately lead to cancer.   However, most of the time, only the "high risk" types have been linked to cancer in both men and women.   Low risk HPV types are 6 and 11. High risk HPV types are 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 68 and 69.

Risk Factors for HPV Infection. Risk factors for HPV are behaviors such as beginning sexual intercourse at an early age (16 years or younger) and having many sexual partners. Some women with high risk, HPV types do not develop cervical cancer.   Research studies have shown that a variety of factors are involved in whether a woman with a high risk, HPV type will develop cancer. The known factors that may increase the risk of cancer include smoking, having many children and human immunodeficiency virus (HIV) infection.

Condoms do not protect against infection with HPV, although it is important to use them to protect against AIDS and other sexually transmitted diseases. HPV can be transmitted from person to person through any skin-to-skin contact with any HPV-infected area of the body, such as skin of the genital or anal area not covered by the condom. Remember, a person may have HPV infection with no visible signs such as warts or other symptoms.

Screening, Treatment and Follow-up of HPV Infection. Screening for cervical cancer consists of a regular Pap test for women who are sexually active. Abnormal cervical cells can be detected during a routine Pap test. If abnormal cells are found the next step is usually <u>colposcopy</u> and a biopsy to further examine the tissue. There is no medical cure for HPV infection. HPV infections that lead to low-grade and high-grade <u>squamous intraepithelial lesions </u>(SILs) are treated using the same methods to eliminate cervical cancer such as cryosurgery, LEEP and laser treatment (See next section, Cervical Cancer Treatment).   In addition there are powerful chemicals such as podophyllin, bichloroacetic acid and trichloroacetic aide) to treat external genital warts. Podofilox also can be applied as a liquid or gel to external genital warts.

How comfortable do you feel about providing information to women about sexual matters? What do you need to make you feel more comfortable?

Screening for early detection of cancer

Breast Cancer. The best method for early clinical detection of breast cancer is mammography. Mammography is a low-dose X-ray procedure that visualizes the internal structure of the breast to detect cancers too small to be felt during a clinical breast examination (CBE) performed by a health-care provider. Mammography detects cancer before the woman can feel the lump herself. Cancers detected at a small size are more likely to be localized; that is, not yet spread. Research indicates that regular mammography and clinical breast exam can reduce breast cancer mortality by 30% among women 50-69 years old. This and other data have led the American Cancer Society to recommend that women aged fifty and over have a screening mammogram every year, and women aged forty to forty-nine to have screening mammograms every one to two years.

Cervical Cancer. The standard method for early detection of cervical cancer is the Pap test. The Pap test is probably the most successful screening test ever developed to detect a cancer. Squamous cell cervical cancer is an ideal disease for screening because there is typically a long pre-clinical phase, which permits early detection. Detection and treatment of precancerous cervical intraepithelial neplasia (CIN) lesions identified by the Pap test can prevent cervical cancer. For women in whom CIN lesions have been detected, the likelihood of survival is nearly 100% with appropriate evaluation, treatment, and follow-up. Cervical cancer mortality rates have decreased 75% since the introduction of the Papanicolaou (Pap) test in the 1940's, proving this test to be an important part of all women's regular health care routine. The American Cancer Society recommends that women have a Pap test and pelvic examination when they become sexually active or at age 18, whichever occurs first. Annual Pap tests are recommended until three consecutive Pap tests are interpreted as being normal. Following this, recommended guidelines are that Pap tests can be performed less frequently at the discretion of the health provider. Glandular cell cervical irregularities (atypical glandular cells and adenocarcinoma) are not always detected by the Pap smear screen.

Summary. Screening mammograms and Pap tests can provide information that leads to early detection of cancer. This is critically important to treatment, if cancer is there. However, in encouraging women to undergo recommended screening and follow-up procedures for breast and cervical cancer, it is important to keep in mind some important information to reduce fearfulness and avoidance. Research has shown that middle-aged women have an exaggerated idea of how likely they are to die of breast cancer in particular.

Screening mammograms frequently show lumps that are benign, a term meaning "not cancerous." Benign does not mean "not painful" nor does it mean "not harmful." Many benign conditions will need to be treated, but women need to understand that these conditions are not cancer.

Both screening mammograms and pap tests may show irregularities and abnormalities that indicate the need for more tests. It is important that women follow through with getting the additional tests, which often rule out the presence of cancer, or indicate treatment for tissue changes in a very early stage. Following through with all recommended tests and procedures can allow a woman to stop worrying when problems are not cancer, and can increase the chances of successful treatment when it is cancer.

A relatively small number of women, compared to all the women who will have screening mammograms and pap tests, will actually have cancer. Most women will not

SCREENING TESTS

Understanding Mammography and the Clinical Breast Exam (CBE)

Monthly self-examinations, annual clinical breast exams, and regular mammography are the main tools for early detection of breast cancer. Most breast cancers are discovered by the patient through breast self-examination (BSE). Another common medical procedure is the **clinical breast exam** (CBE). This is when the breasts are examined by a health professional, using mild finger pressure to detect a lump, as well as to determine whether any neighboring lymph nodes are affected if a lump is present.

Mammography is the best means of detecting tumors that cannot be felt during an examination and for detecting tumors at an early stage of development. Cancers that are found on mammograms, but can not be felt, are usually smaller than cancers that can be felt, and they are less likely to have spread. Mammography should be used in combination with a clinical breast exam.

A mammogram is done with a mammography machine – a special x-ray machine designed for x-raying the breast only. A screening exam typically includes two views of each breast, one from above and one angled from the side. The breast is placed between two flat plastic plates and then they are pressed together. The object is to flatten the breast as much as possible to spread the tissue out making any abnormalities easier to spot with minimum radiation.

The pressure from the plates may be uncomfortable and perhaps painful. This procedure takes only about one minute. Scheduling a mammogram just after your period may reduce discomfort since the breasts are least likely to be tender.

Understanding the PAP Test

A Pap smear is a way to examine calls collected from the cervix and vagina. This test can show the presence of infection, abnormal cells, inflammation and cancer. A Pap test is a simple procedure. A speculum is used to widen the vagina so that the doctor can see the upper part of the vagina and the cervix. A wooden spatula and/or small brush is used to collect a sample of cells from the cervix and upper vagina. The cells are placed on a glass slide or rinsed in liquid fixture and sent to a laboratory for examination.

SCREENING RESULTS

Understanding Mammography Findings

The mammogram is first checked by the technologist and then read by a diagnostic radiologist a doctor who specializes in interpreting x-rays. The radiologist looks for unusual shadows, masses, distortions, special patterns of tissue density, and differences between the two breasts. The shape of a mass can be important too. A growth that is benign (non-cancerous) such as a cyst, looks smooth and round and has a clearly defined edge. Breast cancer, in contrast often has an irregular outline with finger-like extensions.

Many mammograms show nontransparent white specks (calcium deposits) known as **calcifications**. **Macrocalcifications** are coarse calcium deposits. They are often seen in both breasts. Macrocalcifications are most likely due to aging, old injuries, or inflammations. They

usually are not signs of cancer. **Microcalcifications** are tiny flecks of calcium found in an area of rapidly dividing cells. Clusters of numerous microcalcifications in one area can be a sign of ductal carcinoma in situ. About half of the cancers found by mammography are detected as clusters of microcalcifications.

SAFe enrolls women with abnormal findings from a CBE and/or a screening mammogram. A woman with an abnormal finding on a CBE conducted by a health care provider may also need to have a mammogram for further diagnostic determination.

Diagnostic terminology for breast abnormal findings

- **CBE findings**. Abnormal findings include discrete mass/lump (cystic or solid); noncyclical breast pain; spontaneous unilateral nipple discharge; skin scaliness; skin dimpling or puckering; skin ulceration; and skin inflammation.

- **Mammogram.** NBCCEDP programs report abnormal findings from mammography according to the American College of Radiology Classification (ACR). The categories calling for additional diagnostic work are ACR 3-6.

  ACR 3: Probably benign; needs short-term follow-up (e.g. re-screen in 6 months)

  ACR 4: Suspicious abnormality; consider biopsy

  ACR 5: Highly suggestive of malignancy; immediate action required

  ACR 6: Assessment incomplete; needs additional imaging evaluation

Understanding PAP Findings

There are several terms that may be used to describe abnormal results from the PAP test.

Atypia. This term refers to irregularity in the cells. There may be atypical squamous cells or atypical glandular cells.

Dysplasia. This is a term used to describe abnormal cells. Dysplasia is not cancer, although it may develop into very early cancer of the cervix. In dysplasia, cervical cells undergo a series of changes in their appearance. The cells look abnormal under the microscope, but do not invade nearby healthy tissue. There are three degrees of dysplasia, classified as mild, moderate, or severe, depending on how abnormal the cells appear under the microscope.

Squamous intraepithelial lesion. (SIL) is another term that is used to describe abnormal changes in the cells on the surface of the cervix. The word squamous describes cells that are thin, flat and lie on the outer surface of the cervix. The word lesion refers to abnormal tissue. An intraepithelial lesion means that the abnormal cells are present only in the surface layers of the cells. A doctor may describe SIL as being low-grade (early changes in the size, shape, and number of cells) or high grades (a large number of precancerous cells that look very different from normal cells.)

Cervical intraepithelial neoplasia. (CIN) is another term that is sometimes used to describe abnormal cells. Neoplasia means a new abnormal growth of cells. Intraepithelial refers to the surface layers of the cells. The term CIN, along with a number (1 to 3), describes how much of the cervix contains abnormal cells.

Carcinoma in situ. This is the term for a pre-invasive cancer that involves only the surface cells and has not spread into deeper tissue.

Cervical cancer, or invasive cervical cancer, occurs when abnormal cells spread deeper into the cervix or to other tissues or organs. There are squamous cell carcinomas (cancers) and adenocarcinomas (cancer of the glandular cells).

Diagnostic terminologies for cervical abnormal findings

Positive results mean that some of the cells were abnormal or atypical. There are several different systems of classification for cervical abnormal findings. Here is one of the most common, The Bethesda System (TBS), listed in order of severity of the abnormality.

- **AGUS**: Atypical glandular cells of undetermined significance
- **ASCUS**: Atypical squamous cells of undetermined significance
- **LSIL**: Low-grade squamous intraepethelial lesions
- **HSIL**: High-grade squamous intraepethelial lesions
- **Squamous cell carcinoma**: Cancer of the squamous cell type
- **Adenocarcinoma**: Cancer of the glandular cell type
- **Other malignant neoplasms**: This refers to forms of cancer such malignant melanoma, sarcomas, and lymphoma, which affect the cervix only rarely

DIAGNOSTIC FOLLOW-UP PROCEDURES

Follow-up procedures after an abnormal mammogram or CBE

Diagnostic Mammogram. The radiologist will report the findings from the mammogram directly to you or your doctor, who will contact you with the results. Diagnostic mammography may include additional views or use special techniques to magnify a suspicious area or to eliminate shadows produced by overlapping layers of normal breast tissue. The doctor will want to compare diagnostic mammograms with any previous mammograms. If the lump appears to be a cyst, your doctor may ask you to have a **sonogram** (ultrasound study). This procedure directs painless soundwaves at the breast, producing images of the breast tissue. This diagnostic test is sometimes recommended to help the doctor distinguish between a solid and a fluid-filled lump.

Aspirating a cyst. When a cyst is suspected, some doctors proceed directly with aspiration. This procedure, which uses a very thin needle and syringe, takes only a few minutes and can be done in the doctors office. The procedure is not usually very uncomfortable, since most of the nerves in the breast are in the skin.If the lump is indeed a cyst, removing the fluid will cause the cyst to to draw out any fluid. Holding the lump steady, the doctor inserts the needle and attempts collapse and the lump to disappear. Unless the cyst reappears in the next week or two, no other treatment is needed. If the cyst appear at a later date, it can simply be drained again. If the lump turns out to be solid, it may be possible to use the needle to withdraw a clump of cells, which then can be sent to laboratory for further testing.

Biopsy. With certain types of lumps a biopsy is almost routinely recommended. The only certain way to learn whether a breast lump or mammographic abnormality is cancerous is by having a biopsy, a procedure in which tissue is removed by a surgeon or other specialist and examined under a microscope by a pathologist. Keep in mind that most of the time the news is reassuring; at least two-thirds of all biopsies reveal that the abnormality is not malignant.

Tissue samples for biopsy can be obtained by either surgery or needle. The doctor's choice of biopsy technique depends on such things as the nature and location of the lump, as well as the woman's general health.

Surgical biopsies can be either excisional or incisional. An excisional biopsy removes the entire lump or suspicious area. Excisional biopsy is currently the standard procedure for lumps that are smaller than an inch or so in diameter.

An excisional biopsy is usually perform in the outpatient department of a hospital. A local anesthetic is injected into the woman's breast. The surgeon makes an incision along the contour of the breast and removes the lump along with a small margin of normal tissue. The procedure typically takes less than an hour. The woman is discharged the same day after spending a few hours in the recovery room.

An incisional biopsy removes only a portion of the tumor (by slicing into it) for the pathologist to examine. Incisional biopsies are generally reserved for tumors that are larger. They too are usually performed under local, anesthesia, with the woman going home the same day.

Fine needle aspiration uses a very thin needle and syringe to remove either fluid from a cyst or clusters of cells from a solid mass.

Core needle biopsy uses a somewhat larger needle with a special cutting edge. The needle is inserted, under local anesthesia, through a small incision in the skin, and a small core of tissue is removed. This technique may not work well for lumps that are very hard or very small. Core needle biopsy may cause some bruising but rarely leaves an external scar and the procedure is over in a matter of minutes.

Localization biopsy (also known as a needle or wire localization) is a procedure that uses mammography as a guide for placing a thin wire near the abnormality that can be seen on the film, but not felt. The wire marks the area needing biopsy.

Stereotactic localization biopsy is a newer approach that relies on a three dimensional x-ray to guide the needle biopsy of a nonpalpable mass. The patient lies face down on an examining table with a hole in it that allows the breast to hang through; the x-ray machine and the maneuverable needle "gun" are set up underneath. The breast is x-rayed from two different angles, and the computer plots the exact position or the suspicious area. Once the target is clearly identified, the radiologist positions the gun and advances the biopsy needle into the lesion.

Diagnostic follow-up procedures after screening Pap test

Repeat Pap. If the Pap test shows an ambiguous or minor abnormality, the doctor may repeat the test to ensure accuracy.

Colposcopy. If the Pap test shows a significant abnormality, the physician may then perform a colposcopy using an instrument much like a microscope (called a colposcope) to examine the vagina and cervix. The colposcope does not enter the body. A **Schiller test** may also be performed. For this test, the doctor coats the cervix with an iodine solution. Healthy cells turn brown and abnormal cells turn white or yellow. These procedures can be done in the doctor's office. The doctor may also remove a small amount of cervical tissue for examination by a pathologist. A **biopsy** is the only sure way to know whether the abnormal cells indicate cancer.

Following thorough evaluation, cervical abnormalities may require treatment. There are various treatment modalities that remove or destroy the abnormal skin. Each is described more

fully below.

LEEP.   Loop Electrosurgical Excision Procedure is a fast (generally 10-20 minutes) operation that can be performed on an outpatient basis. A speculum is placed in the vagina just like for a Pap smear, and a local anesthesia is injected directly into the cervix to numb the area. After the cervix is numb, a special wire loop conducting an electric current is used as a cutting instrument to excise the abnormal tissue.   The wire loop is hooked up to a special electrical machine and a sticky pad is placed on the patient's leg to complete the electrical circuit.

Cyrosurgery.   Cyrosurgery involves freezing the abnormal tissue on the cervix with a special probe. It is done in outpatient settings using local anesthesia.

Laser Ablation.   This procedure removes the abnormal skin on the cervix with a laser, allowing great precision. It is done on an outpatient basis using local anesthesia.

Cone biopsy.   Cone biopsy is an older procedure in which a large cone-shaped biopsy of the cervix is obtained and then examined by the pathologist. This procedure can also be done on an outpatient basis using local anesthesia.

CANCER TREATMENTS

Some of the women with abnormal findings will be diagnosed with cancer and will need to begin treatment. Women with breast and cervical cancer now have more treatment options and a better chance of long-term survival than ever before. Access and adherence to cancer care is a factor in cancer outcomes. Here are brief descriptions of the cancer treatments for breast and cervical cancers.

Breast Cancer Treatment

The choice of cancer treatment and chance of recovery depend on the stage of the cancer, the type of breast cancer, certain characteristics of the cancer cells and whether the cancer is found in the other breast.

Surgery. The primary treatment for breast cancer is surgery. There are two main groups of procedures for the removal of a breast cancer tumor. They are breast conserving surgery and surgery that involves the removal of the entire breast and surrounding tissue.

Breast conserving surgery is an operation that removes the cancer but does not entirely remove the breast.   A lumpectomy and a partial/segmental mastectomy are two types of breast conserving surgeries.

- A lumpectomy removes the tumor (or lump) along with some normal tissue and some lymph nodes. The lumpectomy is usually followed by radiation therapy applied to the breast. Most lumpectomies are performed as an outpatient procedure in a hospital or clinic. The length of time for the lumpectomy will vary on the size and involvement with the surrounding tissue. In most cases, the procedure requires a general anesthesia during the surgery. A woman can expect to stay in recovery an hour or so and then be released to go home.

Surgery involving removal of entire breast and surrounding tissue

- Total or simple mastectomy is the removal of the entire breast. In addition, some of the lymph

nodes are removed. This is a major surgical procedure that requires a general anesthetic and a minimum hospital stay of 2 days.

- Partial or segmental mastectomy is an operation that removes the tumor along with breast tissue around the tumor, the lining of the chest muscles below the tumor and some lymph nodes. The partial or segmental mastectomy is usually followed by radiation therapy. This surgical procedure requires a general anesthetic and may be performed on an outpatient or inpatient basis depending on the practice of physician.

Surgery involving removal of entire breast and surrounding tissue

- Total or simple mastectomy is the removal of the entire breast. In addition, some of the lymph nodes are removed. This is a major surgical procedure that requires a general anesthetic and a minimum hospital stay of 2 days.

- Modified radical mastectomy is the removal of the breast, many lymph nodes, the lining of the chest muscles and sometimes part of the chest wall muscles. This is a major surgical procedure that requires a general anesthetic and a minimum hospital stay of 2 days.

- Modified radical mastectomy is the removal of the breast, many lymph nodes, the lining of the chest muscles and sometimes part of the chest wall muscles. This is a major surgical procedure that requires a general anesthetic and a minimum hospital stay of 2 days.

Adjuvant therapy. These are treatments given after surgery to increase the chances of removing all cancer cells.

- Radiation Therapy Radiation therapy is the use of x-rays or other types of radiation to kill cancer cells and to shrink tumors.

- Chemotherapy Chemotherapy is the use of drugs to kill cancer cells. The purpose of using chemotherapy as an adjuvant treatment in early stage breast cancer is to prevent the original cancer from returning. Chemotherapy is usually a combination of anticancer drugs, which has been shown to be more effective than a single anticancer drug.   The drugs may be given in a pill or by injection into a blood vessel.

- Hormone therapy   This treatment keeps some types of breast cancer cells from getting the female hormone estrogen they need to grow. Most often, adjuvant hormone therapy is treatment with the drug, tamoxifen. In early stage breast cancer, this drug is known to prevent the original cancer from returning and prevents the development of a new cancer in the other breast. Tamoxifen is taken by mouth in the form of a pill.

Cervical Cancer Treatment

In general the treatment path for cervical cancer is more variable than for breast cancer, and the distinction between diagnostic and treatment procedures not quite so clear-cut. The choice of cancer treatment and chance of recovery depend on the stage of the cancer, the size of the tumor, the woman's age, general health and desire to have children. Below is a brief summary of common treatments.

Surgery. Treatment of cervical cancer usually involves surgery and radiation therapy. Surgery is considered to be a local therapy to remove the cancer in or near the cervix. The type of

surgery will vary by the stage of the cancer.

Surgery for early cancer or <u>carcinoma in situ</u>

- <u>Cryosurgery</u> is a treatment performed with an instrument that kills the cancer by extreme cold or "freezing". This procedure is performed in the physician's office or clinic and no anesthetic is necessary.

- <u>Laser surgery</u> is the use of narrow beam of intense light to kill the cancerous cells.

Surgery for higher stage cancer

- <u>Conization</u> is the removal of a cone-shaped piece of tissue where the cancer is found. This procedure requires a general anesthetic and may involve an overnight stay in the hospital.

- <u>LEEP</u> (as above under diagnostic procedures)

- A <u>hysterectomy</u> is an operation in which the <u>uterus</u> and <u>cervix</u> are taken out along with the cancer. If the uterus is taken out through the <u>vagina</u>, the operation is called a <u>vaginal hysterectomy.</u> If the uterus is taken out through a cut in the abdomen, the operation is called a <u>total abdominal hysterectomy.</u> Sometimes the <u>ovaries</u> and <u>fallopian tubes</u> are also removed, which is called a <u>bilateral salpingo-oophorectomy.</u> This is a major surgical procedure that requires at least one overnight stay in the hospital.

- A <u>radical hysterectomy</u> is an operation in which the cervix, uterus and part of the vagina are removed. Lymph nodes in the area are also removed. The removal of lymph nodes from this area is called <u>lymph node resection.</u> This is a major surgical procedure that requires several days in the hospital and several weeks of recuperation/recovery at home.

Women who have their uterus removed (hysterectomy) no longer have menstrual periods. However, sexual desire and the ability to have sexual intercourse usually are not affected by the hysterectomy. However, many women have an emotionally difficult time after this surgery. A woman's view of her own sexuality may change and she may feel an emotional loss because she is no longer able to have children.

Adjuvant therapy. Treatment given after surgery to increase the chances of removing all cancer cells is called <u>Adjuvant</u> (additional) Therapy. Because the primary purpose of adjuvant therapy is to kill any cancer cells that may have spread, "adjuvant therapy" is usually <u>systemic</u> (uses substances that travel throughout the bloodstream, reaching and affecting cancer cells all over the body).

- <u>Radiation Therapy.</u> Radiation therapy is the use of <u>x-rays</u> or other types of radiation to kill cancer cells and to shrink tumors. In cervical cancer, radiation therapy uses <u>external radiation</u> (using a machine outside of the body) to destroy cancer cells or to shrink tumors. For external radiation therapy, the patient goes to the hospital or clinic, generally *5 days a week for five to six weeks on an outpatient basis.* External radiation may be followed by the implantation of radioactive materials (<u>implant radiation)</u> directly into the cervix. The implant puts cancer-killing rays close to the cancer while sparing the surrounding healthy tissue. It is usually left in for 1 to 3 days and the treatment is repeated several times over the course of 1 to 2 weeks. The patient will stay in the hospital while the implants are in place. Some women may receive external and implant radiation. Adjuvant radiation therapy in combination with chemotherapy is known as "radio-sensitization". This technique is a more powerful way to kill the cancer cells.

- <u>Chemotherapy.</u> Chemotherapy is the use of drugs to kill cancer cells. The purpose of using chemotherapy as an adjuvant treatment in early stage cervical cancer is to prevent the original cancer from returning. Chemotherapy is usually a *combination* of <u>anticancer drugs</u>, which has been shown to be more effective than a single anticancer drug. The drugs may be given in *a pill or by injection into a blood vessel.* Either way, the drugs enter the bloodstream and travel throughout the body.

Risk for Non-Adherence

WHO IS AT RISK?

Certain groups of women are at higher risk for breast and cervical cancer. A higher rate of cervical cancer among Hispanic women has been documented, with rates of up to 2 times higher than for non-Hispanic Whites in some areas. Although incidence rates of breast cancer are lower among African American than White women, mortality rates among African-American women are higher.

As discussed earlier, breast and cervical cancer screening have been shown to reduce morbidity and mortality through earlier detection. Fortunately, thanks to increased patient and provider education, rates of breast and cervical cancer screening are increasing across the country. However, many women still are not using these services or do not adhere to a regular screening schedule. These women are at higher risk because a diagnosis of breast or cervical cancer is more likely to be made at an advanced stage of the disease.

Who are the women who are at greater risk because of not using screening regularly or at all?

These women are likely to be…

- Older
- ethnic or racial minority group members
- Less educated
- Under-insured, or of low socioeconomic status

Despite national advances in expanding screening services for breast and cervical cancer, and improvement in their use of screening, low-income, minority, and older women have lower rates of adherence to abnormal screening follow-up including timely diagnostic resolution, regular re-screening, and cancer treatment. SAFe seeks to improve follow-up adherence for these women by directly assessing for known risk factors and barriers, and addressing them through case management.

RISK FACTORS AND BARRIERS

The reasons for a woman's non-adherence may be complex. They will vary from woman to woman. There is considerable evidence from research about what the general factors contributing to non-adherence are. How these operate in an individual woman and her circumstances can only be determined by the SAFe case manager through careful assessment. To begin with it is important to develop a comprehensive understanding of what can contribute to non-adherent behavior. It is especially critical to recognize the way in which both individual characteristics and circumstances can combine with system and environmental factors to lead to non-compliance. Above all, it is necessary to avoid assuming a judgmental or simplistic stance toward the problem of adherence.

Health Care System Factors

Recent research has identified health care system barriers to optimal adherence to screening follow-up and treatment. Important factors include the following:

- Lack of access to and regular use of medical care

- Transportation difficulties

- Delays in follow-up appointments

- Difficulty in obtaining appointments

- Lack of coordination or single point of access for screening, diagnostic, and treatment services

- Quality and cost of care, inability to pay

- Culturally insensitive or incomprehensible services

Cultural influences

Many research studies have shown that less timely follow-up and inadequate adherence can be partly influenced by culturally-influenced health beliefs about the cause and source of overall health and illness, as well as cancer specifically. These beliefs may shape how a woman understands her abnormal results, what she perceives the meaning to her and her family to be, and what she decides is proper or best to do about it.

Women from ethnic and racial minority groups often encounter health systems and health providers with limited understanding/expertise in their culture and its influence. This can result in misunderstanding, miscommunication, and other barriers to a successful health partnership.

Cultural influences and barriers are an especially important factor. They are discussed and examined in greater depth in the later chapter of the manual "Cultural Competence in Case Management."

Individual Factors

There are a number of important ways in which the woman's own physical and psychological circumstances may influence adherence.

- Having significant **other health problems** (co-morbid health conditions) has been shown to be a risk factor for a woman's adherence with screening follow-up.

- Researchers have observed that **fatalism** among under served population prevails and often prevents them from taking advantage of follow up treatment. In urban areas, poor and/or minority women often do not view cancer screening or follow-up adherence as a high priority in their lives. Basic survival needs – food, shelter, clothing, physical SAFety – consume so much of their time and energy that cancer screening and follow-up become an easily postponed "luxury." Even very modest fees for tests and procedures may be viewed as unaffordable in the face of other urgent needs in the family.

- There is growing evidence that **psychological distress** is an important barrier to adherence among high-risk women. Following a questionable screen women may choose to "wait" to pursue further screening, therefore wasting valuable time. The fear of a positive result and its implications may deter women from seeking medical advice.

- Women may suffer from high levels of **anxiety and depression** as well as other emotional

problems, that are not related to screening and concerns about cancer. Emotional distress from whatever source may interfere with a woman's thinking, problem solving, motivation, and feelings of self-worth, leading to non-adherence. Drug and alcohol problems can also substantially interfere with all of the above.

Discussion Point

Psychological Distress

The sources of psychological stress specifically related to worries about cancer are worth discussing more at this point. It is also useful to review the difference between distress in reaction to actual or feared "bad news," or "worry" and "feeling down" about realistic circumstances, and co-existing mental illness, such as anxiety and depression.

Psychological distress represented by worries about cancer has been found to be high in the face of an abnormal cancer screen and has been shown to be associated with poorer screening adherence, particularly among women with a family history of breast cancer. It is common for people who obtain abnormal results from cancer screening to become worried about having cancer. This fear and anxiety about the possible "bad news" can cause people to avoid follow-up treatment. In cases where women have had relatives diagnosed with breast cancer, their fear of getting cancer may be so great that they refuse to participate in cancer screening altogether.

Poor women often know, or know of someone who died soon after a cancer diagnosis. In medically under-served communities it is often the case that cancers are diagnosed in more advanced and less successfully treated stages. Hence cancer mortality is higher in these communities. As a result, poor and/or minority women may equate a cancer diagnosis with death. Avoiding screening and follow-up with recommendations allow them to feel safer on a subconscious level, since they avoid the possibility of a cancer diagnosis, which in their minds may be a virtual death sentence.

Sometimes symptoms of anxiety and/or depression are at level where they indicate a mental disorder. These are mental illnesses and are different than distress, "worry," or feeling blue. Symptoms of these disorders include disturbances in basic functions such as eating and sleeping, changes in the way one feels about oneself, and changes in the way one thinks about things. Mental disorders are not signs of weakness, nor can they just be "willed" away. Symptoms can last for a long time without appropriate treatment. Most people can be helped with appropriate treatment.

- **Have you or others close to you had experience with depression? How did you think about it? What did you/they do about it?**

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<u>**Socio-economic factors**</u>

- Data suggests that education and income level are powerful predictors of screening and follow-up behavior. Studies highlight that stressful daily lives and competing life priorities for many low-income women can be a deterrent to optimal adherence. When basic needs for shelter, food, or personal SAFety for self or family members are threatened or unmet, women may have difficulty mustering energy and motivation for what are perceived as less important activities in connection with their own health.

- Women's assessment of their personal risk in relation to breast and cervical cancer may be low, in part because of lack of good information.

- The marginal status of many recent immigrants and realistic fear of exposure if they or a family member are illegally in the country, can also be a barrier to follow-up. Women may worry that requests for more information and closer scrutiny of their personal circumstances will accompany further diagnosis and treatment.

- Friends and family members' attitudes and beliefs have been shown to influence a woman's decision to pursue getting necessary health care.

- Availability of social support in the form of at least one other person with whom a woman can share intimate thoughts can influence her ability to cope with the anxiety and uncertainty of an abnormal finding to complete diagnostic procedures and undergo treatment if necessary.

SUMMARY

SAFe's patient navigation/case management initial assessment helps the navigator/case manager determine which of the risk factors described above – **health care system factors, cultural influences, socio-economic factors, and individual factors** -- may be important for a woman. What is important for one woman may not be the same influence on another woman's situation. Also, it may not be one factor alone that is important. For example, indifference or rudeness in a clinic setting may interact with a woman's culturally derived suspiciousness or skepticism about the provider system. It is important to understand the range of different risk factors so that you can do a systematic assessment in the initial contact with each woman.

Cultural Competence in Patient Navigation/Case Management

INTRODUCTION

Perhaps there is no area of life where there are as sharp cultural differences among us as in how we view health and illness and how we actually seek to take care of ourselves. As helpers, our individual beliefs, attitudes and practices are simply taken for granted as "normal" and not something we think about very much until we bump up against someone – typically a patient -who thinks and behaves differently.

The response to experiencing this "difference" can range from highly insensitive and misunderstanding, to understanding but helpless, to culturally competent helping. Perhaps the most typical response in health care, however, is just not "hearing" or "seeing" the difference, which may be hiding behind a patient's silence and retreat from care. Or, providers may believe and value a stance of "culture blindness," believing that this contributes to fair and equitable treatment for everyone, regardless of culture, race, and ethnic background. Fair, equitable and **effective** care for everyone certainly is the goal. But how best to achieve it?

SAFe case management explicitly recognizes that culturally mediated barriers potentially exist in each health care encounter, whether they are "in" the woman, "in" the system's response to the woman, or "in" both. A key responsibility of the case manager is to recognize and understand these barriers, and to use that understanding in furthering the process of health care.

In this section of the training manual we work on developing culturally competent navigation/case management. We will

- Consider the many ways in which people are culturally diverse
- Examine women's culturally-mediated beliefs and attitudes with respect to cancer and some typical health system culture-related barriers
- Define culturally competent case management practice
- Use a cultural competency skill worksheet to identify and increase specific skills

CULTURAL DIVERSITY

Cultural diversity includes differences in shared beliefs and customs that may be associated with gender, sexual orientation, social class, race, ethnicity, physical ability, geography, and other factors as well. Women of diverse groups will be using the services of SAFe. Multicultural sensitivity and competence are important for effective helping. Cultural diversity speaks to the reality of the human race: we are a people of universal humanity and sameness while at the same time we are culturally distinct. Acknowledging cultural distinctiveness goes hand-in-hand with respecting fundamental human rights, and respecting the rights and responsibilities of all members of a society as individuals and citizens.

Cultural competence begins with recognizing that we all have culturally distinctive attitudes and beliefs if we learn to listen for and recognize them, and, at the same time, learn to approach each person as a unique individual.

Commonly used cultural labels over-simplify the true reality of cultural diversity in US society today. Cultural labels such as "Hispanic" include persons of diverse ethnic background and distinct cultures including Mexican, Puerto Rican, Dominican, Cuban, and many Central and South American countries. Similarly, "African-American" includes persons who are native-born as well as of Caribbean and African heritage. The same is true of the label "Asian" which includes such diverse cultures as Indian, Chinese, Vietnamese, Korean, Japanese, and different Pacific Island cultures. Many individuals identify with more than one culture based on family of origin or through marriage. SAFe staff should avoid making assumptions about an individual woman based on her ethnic or racial "label."

CULTURAL INFLUENCES AND ADHERENCE

Earlier, Section Two of the training manual discussed common barriers to adherence. They included cultural influences. Many research studies have shown that women's own culturally-influenced health beliefs about the causes and sources of overall health and illness, as well as cancer specifically, can contribute to less timely follow-up and inadequate adherence. Women who have lived less time in the US, or have remained more centered within their original culture are at particularly high risk.

Just as important, clinics, hospitals, and health providers may be unaware, insensitive or poorly equipped to deal with the cultural differences presented by their patients. Most obvious is the inability to communicate because of language/translator barriers. But there are less obvious barriers within the health care system as well.

Some patients face unique barriers associated with their recent immigrant status. Legal difficulties in the US or severe trauma in their home of origin, are examples of life circumstances, quite apart from the abnormal screen itself, that may contribute to non-adherence.

Culturally-influenced health beliefs

The specific content of these beliefs and attitudes may vary greatly from group to group. What follows are some examples. Keep in mind that the point of these examples is to increase sensitivity to our own beliefs and values that we take for granted, and to increase capacity to listen for culturally different views and thinking.

❖ Women or their family members may believe that breast cancer and/or cervical cancer is caused by promiscuity, rape, sexual abuse or other behaviors that are considered shameful in that culture.

❖ Women may fear negative reactions from employers and others.

❖ Women may have very little awareness, knowledge or misinformation about screening, results, and/or diagnostic procedures that are recommended.

❖ Women may believe that trauma or injury to the breast can cause cancer.

❖ Women or their family members may believe that any effort to cut into tissue that could be cancer will only cause the cancer to spread.

❖ Women may believe that only traditional healers and traditional medicines can successfully help a problem, or may want to try alternative healing practices.

❖ Women may believe that spiritual forces are responsible for physical symptoms and seek spiritual solutions only.

❖ Women may have strong faith-based attitudes that discourage intervention in what may be God's will.

❖ Women may fear the reactions of male family members to their receiving intimate medical tests and procedures from male medical practitioners

❖ Women may defer decisions about their health care to husbands or other authority figures in the family.

❖ Women or their family members may believe that cancer is contagious.

❖ In some cultures it is taboo to talk about cancer at all or even to say the word.

"Sarah is a 24 year old young lady. She migrated here 4 years ago. She had a lot of traditional ideas, like what women's roles were supposed to be. She was worried because of her abnormal PAP smear and she wasn't getting pregnant. She was really upset because she felt a woman who could not get pregnant wasn't as worthy as other women that could bear children. She really believed her abnormal PAP was saying there was something wrong with her and she would be infertile and if she couldn't get pregnant then what difference did coming back (for follow-up and repeat PAPs) make."

Discussion Point

❖ What culturally distinctive groups are served by your site(s)?
❖ What are some other possible examples of culturally determined health beliefs in your own communities?
❖ What are things that you hear women say about cancer, cancer screening, and follow-up tests and treatment?
❖ How are some of these beliefs and ideas different from your own thoughts and feelings?

Health provider and health system culture-related barriers

Clinics and providers often believe they are providing "culture-blind" services to all, regardless of race, ethnicity, or other cultural distinctiveness. But then cultural barriers are invisible too. Or health care systems simply may not be equipped to provide culturally sensitive and competent services, even while acknowledging the need. Here are some examples of health system culture-related barriers.

❖ Doctors and other clinical staff do not speak the patient's language or speak it too poorly to express/understand important details.

❖ Staff overestimates the patient's ability to understand/speak English.

❖ Translators are not available.

❖ Staff use family members to translate (including children) without checking/considering the patient's preference or willingness.

❖ Instructions for procedures/medications are only in English.

❖ Providers have limited time with patients to discuss concerns and patients are not confident about asking questions.

❖ Providers criticize or challenge patient's use of "home remedies" or alternative health practices/providers.

❖ Telephone operators only speak English and rush with information when it is provided.

❖ Providers misunderstand the expected role and input from key family members (either to include or exclude).

❖ Providers and clinical staff often mistake silence for understanding.

❖ Providers and staff often mistake quick verbal agreement ("OK," "Yes, ma'm") or head nodding for true agreement or willingness.

❖ Staff routinely asks without explanation for personal information that may violate a patient's sense of privacy.

❖ Staff asks for information that arouses a patient's fear of being reported to authorities.

❖ Staff dismisses a patient's concern or fear as "silly" or "ignorant."

Discussion Point
Discussion Point

Take time now to identify any culture-related barriers that could be operating in your clinic/health care setting?

CULTURAL COMPETENCE

Culturally competent SAFe navigation/case management practice means developing specific knowledge and skills to effectively assist culturally diverse patients achieve adherence. Cultural competence means the ability to "bridge" cultures in providing health care so that relevant elements of the patient's culture of origin and elements of the dominant (health system and provider) culture are successfully brought together to achieve health-relevant goals. The culturally competent case manager will often be **mediating** between cultures. This may mean explaining to, pointing out, interpreting for, and educating either or both the patient and the provider(s).

Cultural competence includes a strong personal cultural identity that allows the case manager to move comfortably between cultures without feeling alienated or threatened. It also demands open-mindedness and willingness to explore and learn from patients about their culture and their personal uniqueness within their culture. When the case manager is of the same culture as the patient, an important part of cultural competence is recognizing that individuals from the **same culture** do not necessarily have identical beliefs and views. Finally, cultural competence means recognizing when a barrier or influence is **not** culturally influenced.

It is impossible to know all the important information about each culture. However, there are some common themes that you can keep in mind. Use the discussion points below to consider how these themes may present themselves with the women from the primary cultural groups served by your clinic.

Discussion Point

Here are three themes to keep in mind. How are they relevant to the women served in your clinic?

❖ **Respect.** Patients are sensitive to your verbal and non-verbal indications of lack of respect, such as failure to use a person's last name, or not giving your full attention. Patients are anxious to know that you are a person of goodwill who does not think less of them because of their cultural background. Discussing intimate, personal problems may be difficult for patients for fear of losing face with you or others. Finally, some patients may try to be respectful of the doctor by not complaining or questioning.

❖ **Understanding.** Patients need to feel that they are understood. When the patient's language usage, cultural practices, specific words, and beliefs are unfamiliar or unclear to you it is not helpful to proceed as if you understand. Asking the patient to explain does not make you seem incompetent. It tells the patient that you really do want to understand her.

❖ **Acculturation.** Minority women will differ in how long they have been in this country and to what degree they feel connected to their ethnic community.

CULTURAL COMPETENCIES FOR PATIENT NAVIGATION/CASE MANAGEMENT PRACTICE

Below we present an outline and brief discussion of a set of basic competencies. They consist of three areas 1) cultural awareness; 2) knowledge; and 3) skills. Following the material there is a self-assessment tool that the SAFe case manager can use to rate her own level of competency. Keep in mind that the competencies are expected goals, and that it takes time, experience, and work to achieve them. SAFe staff may want to use the self-assessment form during training and then re-assess at a later point. [The competencies and self-assessment tool are adapted from Doman Lum (1999).]

Competency: Cultural Awareness

This refers to the case manager's growing awareness of the role and presence of culture in her own, the clients' and the health care system's behaviors, attitudes, and world views. The competent case manager is

✓ **Aware of her own life experiences as a person related to a culture (e.g. family background, household and community events, beliefs, and practices).**

✓ **Aware of her own positive and negative experiences with persons and events of other cultures and ethnicity.**

✓ **Aware of how her own thinking, feeling and acting reflect aspects of racism, prejudice, and discrimination.**

Competency: Cultural Knowledge

This refers to the case manager's growing base of reliable information concerning different cultures. The competent case manager

✓ **Knows the basic demographic information (numbers, other significant characteristics) about the culturally diverse populations served by the clinic.**

✓ **Understands some of the background and history of oppression experienced by different cultural groups.**

✓ **Knows about the strengths existing in the individuals and social milieus of people of different cultures.**

✓ **Knows about alternative medical practices that may be important to diverse cultural groups.**

✓ **Knows about the values that are important to diverse cultural groups.**

Competency: Skills

This refers to the case manager's ability to apply awareness and knowledge to her efforts to help the patient. The competent case manager

✓ **Understands how to overcome the resistance of a patient and develop trust.**

✓ **Uses a positive and open communication style.**

✓ **Helps the patient explain her situation in her own terms.**

✓ **Looks for strengths and capabilities to support the patient in helping herself.**

✓ **Speaks the language of the largest cultural group served by the clinic and works to identify translators for other groups.**

✓ **Identifies health-related and other community resources that are specifically targeted to a cultural group (for example, offers information or support groups in the patient's language; church-related assistance; specialized legal assistance for immigrants).**

Cultural Competencies Self-Assessment

Use the following work sheet to rate yourself on your level of competency in the areas listed. Use a scale of 1 to 4: 1=Very much; 2=Somewhat; 3=Slightly; 4=Not at all.

<u>Competency</u>	<u>Rating</u>
1. I am aware of my life experiences related to a culture.	_____
2. I have contact with individuals of other cultures and ethnicity.	_____
3. I am aware of positive and negative experiences with persons and events of other cultures and ethnicity.	_____
4. I am aware of my own thoughts, feelings, and behaviors that contain elements of racism, prejudice, and discrimination.	_____
5. I have knowledge of demographic information for the diverse cultural groups served by the clinic.	_____
6. I understand the history of oppression experienced by many cultural groups.	_____
7. I know about the strengths of people in diverse cultural groups.	_____
8. I know about culturally diverse values.	_____
9. I understand how to overcome the resistance and lower the communication barriers of clients from diverse groups.	_____
10. I have a positive and open communication style.	_____
11. I help the patient explain her situation in her own terms.	_____
12. I look for strengths in each patient.	_____
13. I regularly identify resources that are specifically targeted to the cultural group(s) served at the clinic.	_____

Empowerment Practice: Increasing Health Competence

WHAT IS EMPOWERMENT?

Empowerment means helping patients connect to their own power through discovering and using resources and tools inside of themselves and around them.

Power for the patient means …

- greater capacity to do for herself
- a sense of personal control
- ability to affect those around her

Empowerment practice requires a helping relationship based on "good enough" trust and working with the patient, not for her or just telling her what to do.

Empowerment for greater health competence is the specific use of empowerment practice in **SAFe** case management to increase a woman's adherence right now and her health-related behaviors in the future.

EMPOWERMENT AND PROBLEM-SOLVING IN SAFe

SAFe's systematic initial assessment is designed to identify a wide range of problems and barriers. Problem-solving is a key activity of the initial contact. Using an empowerment approach starts from the very beginning in problem-solving together with a woman.

An empowerment approach to problem solving involves matching what a woman can do for herself with the problem-solving efforts, no matter how small a part of the effort that may be.

General guidelines for empowerment-based problem-solving

Here are some important ideas to keep in mind about problem-solving in empowerment practice, no matter what type of problem has been identified.

- Identify the problem clearly from the **patient's point of view** and be sure that you and the woman have the same understanding of the problem to be solved. If the problem or concern seems very serious to you, this may mean you will refer the woman directly to the MSW for further problem exploration and problem solving. If not,

- Ask for a woman's ideas about how to solve the problem, and find out about previous efforts to solve the problem. **Listen for strengths** the woman may have. At this point you may decide that the woman will be able to solve the problem herself, or may be able to do so with encouragement and suggestions from you.

- If needed, generate additional ideas about solutions. You and the woman might both need to do this together, and you may need to **provide additional information about a resource**. If you judge that she can contact/arrange for the resource herself, provide the name, telephone number, and contact person (if known) for a resource that you recommend.

EXAMPLES OF EMPOWERMENT STRATEGIES FOR COMMON ADHERENCE BARRIERS

Barrrier: Poor communication with provider(s)

Empowerment Strategies…

- Clarify and educate about any information that is unclear or not fully understood
- Encourage the patients to ask questions about any aspect of a test, procedure or recommendation. Talk with her later about what she found out.
- Confirm that her questions are good ones and her doubts or uncertainties are valid and important.
- Coach a patient in how to ask a question.
- Help patient identify questions and concerns and write them down. Rehearse how she will go about asking them.
- Model how to ask questions and how to persist until she is clear and satisfied.
- Find a provider who can speak the patient's language.
- Accompany the patient to assist with translation.
- Arrange for translation.

Barrier: Clinic barriers and obstacles

Empowerment Strategies…

- Explain to the patient how things "work."
- Teach a woman how to assert consideration of her needs when scheduling appointments (e.g. to minimize time off from work or other commitments)
- Provide an up-to-date list of telephone numbers a woman may need.

Barrier: Patient beliefs, attitudes, preferences that interfere with adherence

Empowerment Strategies…

- Explore, understand, and then educate
- Urge the patient to discuss any alternative treatments with her doctor.
- Emphasize the patient's need to take care of her own health for her sake as well as the sake of others who depend on her.
- Educate the patient that medical problems, including depression, can be helped and are not "just the way life is."

Barrier: Family, work, legal, financial, etc.

Empowerment Strategies

- Provide information and contacts for needed resources. If needed, follow-up and encourage the patient to make the contact.
- Explain how things "work."
- Support the patient in sharing accurate and specific information about her health status and care with family members/loved ones who may question or interfere.
- When there are many problems, help the patient prioritize and tackle one at a time to make some progress.

Skills for Effective Helping in SAFe

ESTABLISHING RAPPORT ON THE TELEPHONE

There are several guidelines to keep in mind when contacting people over the telephone. All purposeful helping is based on some minimal amount of trust between the helper and the person to be helped. Building trust begins with the very first words you say.

Here are some important points…

☎ Identify yourself clearly by giving your name and stating the purpose of the call.

☎ On the telephone it is more difficult to know if a person is getting confused or fearful in response to your call or what you are saying. Keep your messages and your tone clear and simple.

☎ Communicate warmth and interest, but do not act overly "friendly." Being too informal or casual confuses people about why you are calling. Focus on the tone and pitch of voice (your own and the patient's).

☎ Do not rush the woman you are calling. Give her time to pause and be silent before answering anything you ask.

☎ Do not jump to conclusions about what the woman may mean. If you do not understand what the client is saying, ask her to clarify or give you an example.

☎ Never express surprise or disbelief in response to what the woman tells you.

☎ When you do not know the answer to a question asked by the woman, explain this in a non-apologetic manner and offer to find the answer, if appropriate. Be careful not to make promises that you may not be able to keep.

At the end of a call, let the woman clearly know what you will do next. Be sure she has your full name and telephone number.

QUESTIONING, LISTENING, AND RESPONDING WITH EMPATHY

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The purpose of this section is to apply basic interviewing and relationship skills to the scripted first telephone contact. The script and protocol are used to assure that the educational material is presented accurately and precisely, and to make certain that the risk assessment covers the same information for each woman. However, the telephone call must also be a natural and comfortable exchange for the case manager and the patient. This takes practice. Some review of basic issues in questioning, listening, and empathic responding follows.

The telephone interview protocol asks questions about finances, access to medical care, problems with the clinic and/or staff, family stresses, worries and concerns that could be barriers to completing follow-up recommendations. You are asking questions to learn about an individual woman's risk circumstances so that you can help her address them in an appropriate way. You are questioning, listening, clarifying, and responding to her concerns in a way that lets her know you have understood her feelings. This requires you to use basic skills in questioning, listening, and empathic responding.

Effective Questioning

Direct questions. The protocol prompts you to ask direct questions; that is, the specific topic of interest is clear and specific.

For example,

- **Have you ever had a mammogram before this one?**

- **Were you treated politely during your last clinic visit?**

Or

- **Some women are concerned about the costs of exams. Do you have any questions or worries about the cost of the exam?**

Some women will simply answer these questions "yes" or "no." You want to follow up an answer that indicates potential problems or concerns with "can you tell me more about this?" Sometimes women will tell you more; for example, will begin to explain what the question or worry is. They may begin to tell you about their general circumstances and pressures, even when these are not directly related to the issue of paying for diagnostic exams. Because you need to cover all of the areas in the telephone protocol, and do so in a limited amount of time, you will sometimes find yourself hearing information that you believe is important for your assessment of level of risk, but not be able to respond to in any depth in this telephone call. This calls for judgment on your part in finding a balance between listening and asking more questions that are not on the script in order to be clear what the problem is, and holding to the focus of the script.

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Open and Closed Ended Questions. While all the questions you ask are direct questions; that is, clearly asking about an identified issue, the script consists of both open and closed questions to elicit information. Closed questions involve brief, factual information, which often can be answered simply "yes" or "no." Some examples of closed questions in the telephone protocol:
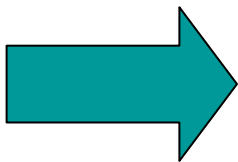
- **Do you have medical insurance?**

- **Many women say that they sometimes just forget about their medical appointments. Is this true for you?**

- **Do you completely understand the [needed follow-up procedure] and why it is needed?**

Open direct questions encourage more than one word answers and tend to encourage the woman to self-disclose. They help exploration of possible problems since they allow a woman to identify what, from her perspective, are likely to be key concerns. Open questions, by allowing a woman to talk more freely, give you a better idea of what she is thinking and feeling. At the same time, a woman's response to open questions can lead you away from the focus and central purpose of the call. Again, achieving the balance between listening and eliciting information that will give you a better picture of the woman and the risks and barriers to follow-up in her situation will be your goal. Here is an example of an open question in the telephone protocol.

- **Some women have other personal, family or other problems that seem more important than following recommendations about your mammogram. Are you having any particular problems that make it hard for you to follow-up on the recommendations? Yes? Can you tell me more about these specific problems?**

It is important to follow the telephone protocol closely in your telephone interview. We want to be sure that each woman receives the same service. But the telephone interview also needs to be a genuine and natural exchange, not just a rote exercise. And you want to learn about the true feelings and circumstances of each woman, no matter how unique or unusual. Your skill and judgment are crucial to a successful intervention.

Effective Listening

Listening means paying careful attention to the communication of the other person. Effective listening begins by not allowing any distractions to your careful attention. Active listening is based on working to attend to the various levels of communication. Communication can be verbal (words) as well as non-verbal (actions, sounds, body language). Telephone communication eliminates some aspects of non-verbal communication, but by no means all. Communication is the content of the words but also the tone and pitch of the words, which provide clues to the emotional meaning of the words. The emotional meaning of words can be different than the literal meaning. What is said is not always what is meant and vice-versa. Active listening also involves checking to be sure that your understanding of what you are hearing is correct.

Effective Empathic Responding.

Empathy is the ability to understand the emotional experiencing of the other person. There is a great deal of evidence showing that a condition for establishing counseling rapport is the client feeling "understood." Empathic responding requires **you to understand** and the **woman to experience your understanding**. This is empathic responding.

Some of the women you talk with will be distressed and upset about their circumstances. Others may be defensive and wary about your calling. Your questions and probing about needs and problems may lead them to express their feelings directly or indirectly. Even though you are following a script it is important to use empathy skills to listen and respond to what a woman is saying and how she is saying it with accurate understanding of the feelings that lie behind the words. Acknowledging the feelings when you are aware of them is helpful for building rapport, for getting a true picture of a woman's situation, not just answers to a question, and for providing emotional support to the woman. As you conduct the first telephone counseling session remember that you are helping a woman do what is best for her in attending to her health needs. Listening to her difficulties and responding to the feelings that are there lets her know that you understand her and accept her and her feelings as a starting point. This is often the first essential step to any further helping.

Severe Emotional Distress

SAFe's baseline assessment includes a question about suicidal thoughts (see initial contact script). This question is one component of the mental health screen/assessment. It is rare that a woman will answer anything other than "not at all" (Score of "0") to this question, but it is possible. The case manager **immediately** should do the following in the case that a woman answers positively to this question (Score of "1, 2, or 3")…

- Notify the clinic administrator
- Place a note in the woman's medical chart

The case manager should also refer to the MSW for further assessment.

Discussion Point
Discussion Point

Take time now to role play the initial contact with a patient in SAFe. Refer to the Service Manual and the explanation of what this contact is expected to accomplish. Use the script (Initial Contact Form) provided in the tool kit as you do the role play.

There are several role scenarios provided in the supplemental training resource section. Choose several and practice with a partner, with one person playing the client and the other the case manager, and then switching roles with another vignette.

After each role-play, together go over the experience, paying particular attention to the different

skills that have been discussed.

In one role play, have the patient meet criteria for referral to the MSW and then have the patient be quite resistant to the idea. Practice making the link to this other helper effectively (see Service Manual "Step-by-step" for additional discussion and strategies of this key task.)

- Identify places of discomfort (for the case manager; for the patient).
- What caused the discomfort? What could you try differently?

_____

_____
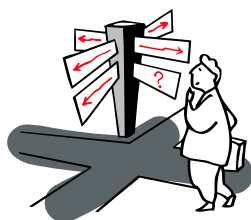
SEX EDUCATION

Earlier in the training we discussed information about the causes of cervical cancer and the role of the sexually transmitted virus HPV. For many women with abnormal PAP smears the case manager will need to provide information about the virus as well as other sexually transmitted diseases (STDs), answer questions about the relationship of HPV to cervical abnormalities and possible cancer, and explore women's understanding and feelings in relation to sexual matters. This is a sensitive area that may feel uncomfortable for both the patient and the case manager. It is important for the case manager to educate herself first, and develop personal comfort with the topic so that she can be in a position to assist the patient with her feelings and her need for accurate information. Below are general guidelines for these important discussions.

- Prepare the patient by telling her that you are planning to educate her about HPV, STD's and sexual behaviors. Let her know you understand this may feel uncomfortable but the topic is important for you to address together since it is important for her health and wellbeing. Inform her that as part of the cervical cancer education you are providing, educating her about HPV and STD's is equally important and related to medical issues.

- Emphasize the importance of health and self care in relation to being able to continue to care for one's own family. Empower patients by informing them that the more knowledge they have the more control and decision making power they will have.

- Be sensitive yet direct in informing women that is important to be become aware of STD's, safe sex, HPV and how it relates to cervical cancer. When providing general sex education and HPV information it is helpful to clarify and employ the terminology the patient herself uses.

- Present the information in a matter-of-fact manner by using literature - such as pamphlets providing a simple explanation of HPV and cervical cancer - as an educational tool. Pamphlets can lead to a more general discussion of sexual matters and prompt questions the patient may have.

- Discussion of sex is considered taboo in certain cultures, so it is important not to push the topic of HPV and sex education when the patient refuses to discuss this. In that case, tell the patient you will leave with her literature in the appropriate language regarding HPV or other sex education materials. Encourage her to read through the materials and to call you with any questions.

- When providing a general explanation of HPV, STD's and cervical cancer, it is important to encourage the patient to discuss details of her specific diagnosis with her physician such as an abnormal pap smear or cervical cancer diagnosis.

- Keep in mind that when discussing these issues some patients may jump to the conclusion that their partners are involved in infidelity. In this case, assure the patient that a diagnosis does not mean that partners are being unfaithful and emphasize to the patient that your goal is to educate patients.

- Be prepared to refer patients to family planning or a specialized clinic when they have more questions regarding sex education and safe sex.

- Assess the patient's level of understanding of the information you have provided by asking "Now that you know about this information what do you plan to do with this information?"

- Practice and use role playing as a way to develop greater comfort in presenting sex education and HPV information.

SYSTEMS NAVIGATION

Systems navigation is based on a tested approach to service. It is designed to help patients with abnormal findings in navigating the health and human services bureaucracies to accomplish necessary follow-up and treatment procedures.

Systems navigation directly addresses barriers to follow-up that arise in the site provider system (missing mammogram films, scheduling problems, etc.). It also addresses through referral, linkage, and problem solving environmental barriers that involve other human resource systems (transportation, child or eldercare, other medical needs, emergency housing and welfare).

Effective systems navigation requires a comprehensive understanding of the site provider clinical environment and its processes and personnel. With this knowledge the likely sources of and solutions to patient-reported difficulties can be quickly and accurately determined. A good working knowledge of the resource environment external to the clinical setting is needed as well.

Systems navigation requires skills in three primary areas:

- Empowerment skills so that patients are helped to undertake as much problem-solving themselves as feasible and appropriate
- Skills in problem-solving combined with an approach that is assertive, persistent, and constructive
- Skills in making referrals that successfully link patients with needed resources

MAKING AN EFFECTIVE REFERRAL

An important activity for the SAFe navigator/case manager is to link women with the community resources and services that can help with problems and needs that may interfere with follow-up.

Many people view referral as a relatively simple task. However, research studies indicate that many attempted referrals end in failure, possibly as many as 50%. This means that the process of making a referral successfully is actually quite complex. Here are some guidelines to follow in making referrals:

- Make a referral for a specific problem that the client has agreed she wants help with.

- Make a referral for a service or resource that the client agrees could be helpful and work for her.

- Don't automatically refer if you can solve the problem directly. Since the client is already involved with you, your chances of success are probably greater.

- Be realistic about what other agencies and professionals have to offer. Know their services and method of operating.

- Check with the woman to be sure that she isn't already involved with a similar resource or service before making a new referral. If she is, explore the reasons that the resource is not being used/helpful. This may require some systems navigation.

- Before deciding on a formal referral to an agency, consider the client's friends, relatives, neighbors, natural helpers, and other informal resources as a source of assistance.

- Keep in mind the practical barriers that can interfere with a woman using a resource (transportation, child care, inability to take time from a job, and so forth.)

- Let a woman tell you about her past experiences with similar resources or services. Many have had negative experiences. Their feelings and concerns need to be addressed.

- Assume the woman is ambivalent about the referral. Although she may want the help, she may be fearful. Explore the woman's ambivalence ("yes, but") and help her express concerns and any reluctance about using a resource.

- Whenever possible clients should make their own arrangements for the service or resource, assuming as much responsibility as possible. If a referral is critically important to a client, however, you should do whatever is needed to establish the linkage.

- Increase the likelihood of connection to the resource by providing in writing all the necessary information, including directions, telephone number, and, if possible, the name of a specific person to contact.

- Use check back (asking the woman to call you after the initial contact to let you know if it was helpful or if she encountered difficulties) to encourage referral success and to evaluate the usefulness of the resource. Use systems navigation with the resource if necessary.

COMMUNICATING WITH OTHER HEALTH CARE PROVIDERS

In earlier sections we have stressed the critical **case management functions** of 1) **educating** a woman about the meaning of her results and the specific diagnostic procedures that are recommended; and 2) **empowering** the woman herself (through coaching, modeling, rehearsal, etc.) to ask the provider questions and express concerns and views directly. In some cases, the case manager will need to actively facilitate better communication and understanding between a

patient and another health care provider, often a physician. This is the **bridging or brokering function**.

As we have seen, common barriers to adherence include

- a woman's incomplete understanding of the meaning of results and recommended diagnostic/treatment recommendations
- a woman's reluctance or lack of opportunity to ask questions or express her views directly to the provider
- inability to communicate at all because of language barriers
- culturally influenced differences in view and misunderstandings on the part of either or both the woman and the provider

Bridging as collaboration

There will be circumstances when the navigator/case manager needs to communicate directly with the provider to accomplish the necessary "bridging" or brokering between provider and patient. In providing bridging assistance between a patient and one or more health care providers, the case manager is **collaborating** with providers of the health care team.

> "Collaboration may be defined as a cooperative process of exchange involving communication, planning, and action on the part of two or more disciplines. Its purpose is to achieve specific goals and tasks related to health care that cannot be achieved, or achieved as well, by one discipline (or individual) alone." (Germaine, 1984 "Collaborative Practice in Health Care" in Social Work Practice in Health Care. New York: The Free Press, p. 189)

Here are examples of what might need to be communicated and discussed.

- Providing background information and explanation of the cultural meaning and importance of a woman's (or family member's) stated views, preferences, and other behaviors.
- Informing the provider of the nature of a patient's misunderstanding or confusion (when the woman cannot or will not do this herself).
- Informing the provider of a patient's circumstances adversely impacting adherence and care, such as symptoms of major depression, sudden homelessness, losing a job, drug or alcohol use, domestic violence.
- Obtaining more understanding or detailed information about what is being recommended by the provider, why it is being recommended, and what the patient can expect to experience from the procedure or test.
- Informing the provider of reasons given by a patient who is refusing to adhere or follow recommendations.
- Assisting with interpreting or obtaining interpreting services for the care encounter.

Effective communication is the key to successful collaboration and the bridging role.

Competencies for effective communication with other health care providers

Navigators/Case managers will find that effective communication will not happen automatically. It requires developing positive attitudes, taking risks, and using good interpersonal skills such as empathy, focused listening, and clarification. Here are some important competencies:

- Manage your own feelings. At first you are likely to over-identify with the patient against the provider(s) with whom there may be difficulties. You cannot help the patient get what she needs if you respond in a way that cuts her off further from that helper.

- Avoid stereotyping other professionals. "The doctors just want to tell the patients what to do." Or "The nurses are too busy to help."

- If possible, first build a face-to-face relationship. Look for an opportunity to introduce yourself to the providers with whom you will be working. Give a short explanation of your role and expected contribution to patient care.

- Maintain appropriate self-confidence in yourself as a valuable member of the health care team and a realistic sense of your own competence, even when others are unclear or uncertain or even unwelcoming about your place or role.

- Accept the responsibility to open communication. Do not expect others to come to or contact you.

- Do your homework and know what you are talking about before initiating contact. Think about the questions the provider might have and be prepared. Do not raise issues about which you are uninformed or are not in your area of responsibility.

- Don't hesitate to ask for clarification or a definition of terminology that you don't understand. It is better to ask than to pretend you know.

- Be conscious of the other person's circumstances – schedule, time demands, responsibilities, and "world view" – and respect them. Remember that in general doctors may not expect to be "sharing" a patient with you, and may not be aware of what you are doing.

- Be aware ahead of time that differences in age, gender, social class, income, education, and race can contribute to misunderstanding and less effective communication between you and another health care provider. Anticipate your own reactions to these potential differences to minimize their effect.

- Be respectful and courteous in your communications, even when you feel the other person may be showing you less respect and courtesy than you would like. Remain non-judgmental and don't personalize the encounter.

- Listen. Keep cool, and don't argue.

COMMUNITY RESOURCES

The SAFe navigator/case manager needs a detailed working knowledge of the services and resources that are available in their community. They need to know as well the significant resource gaps and common strategies to try to fill them. This information is critical to the effectiveness of helping efforts. It is also time consuming and painstaking to acquire, and changes periodically.

The necessary service and resource information is of two general types:

1. Information about the health care system and payment mechanisms that are directly relevant to

the cancer screening, diagnosis and treatment services that women need

2. Information about ancillary resources to address barriers to adherence, such as transportation, child and elder care, and specialty mental health services. [Informal versus formal resources]

Health care resources

The greatest resource need of the women served by SAFe will be resources to help with the cost of health care. Before beginning to provide services in SAFe, as case manager you must familiarize yourself with the specifics of the medical care system pertaining to low-income women, including what is most problematic in your locale. This includes knowing…

- Medicaid eligibility rules and procedures and what is covered and what is not.
- BCCEDP program coverage rules
- Special state programs to pay for cancer treatment, medications, etc.
- Additional sources of affordable care

Providing detailed information about specific health care resources is beyond the scope of the SAFe training and it is strongly recommended that a hospital social work department serve as a training resource for this information. Because access to care is a critical and frequent barrier to follow-up, it is essential that the SAFe staff understand where the problems with access are likely to occur and what alternatives are available. Understanding how the system can and should work is also necessary in the case that access is not really the difficulty, but something else is.

Other Resources

SAFe attempts to address resource barriers that directly interfere with adherence, whatever the barriers may be. This is done by identifying and linking with appropriate resources when they can be found. The case manager must develop knowledge of available resources, use creativity and advocacy in finding new resources, and cultivate a network of relationships with frequently used resources. It is also important to understand that SAFe will try to help with any (not just certain pre-determined) resource needs, provided that the need is directly related to adherence. This potentially wide-ranging resource mandate is a demanding part of SAFe service delivery, but a typical situation for human service professionals today. It is expected that the most frequently needed resources will be transportation and specialty mental health services.

Culturally targeted resources

Culturally competent case management includes knowing about and helping women access resources, including less formal ones that are specially designed for persons of an identified cultural group. Some examples are cancer support and information in a woman's native language, specialized legal resources, neighborhood health care clinics, and church-based child care/transportation assistance

Up-dating Services and Resources

It is important to note changes to the resource listings as they are used so lists can be updated periodically.

Watch for and attend in-service training sessions of the host social work department or community information exchanges to keep abreast of new resources and changes in rules and procedures for existing ones.

SAFe should assign one person to represent the program at any meetings of providers, NBCCEDP

partner meetings, and local community meetings that identify and address questions of resources and changes in resources in connection with low-income women's health and health-related needs. The SAFE representative can provide important feed-back on resource gaps and difficulties for its target clients as well as keep abreast of changes and their implications for resource availability.

Additional Training Resources

CASE EXAMPLES FOR ROLE PLAY: INITIAL CONTACT

Mrs. Walters (Mammography)

Mrs. Walters is 52 years old. She is a native of Jamaica and moved to the US in 1965. She is ahigh school graduate with 2 years of college. She is divorced and lives alone in a rooming house. She has spent much of the pat year in a shelter for homeless women. Her mother had breast cancer and a mastectomy but this does not overly concern Mrs. Walters.

Mrs. Walters had pain in her right breast 4 months prior to having the index mammogram at the clinic. She received a letter stating that she needs a sonogram in the left breast, but she has not scheduled this yet. She is confused since the pain was in her right breast. She also has high blood pressure, but is not currently being seen for this. She has received psychiatric treatment in the recent past, but also is not currently getting any treatment.

Ms. Davis (Mammography)

Ms. Davis is a 71 year old native of South Carolina. She is widowed and lives with her only surviving adult child. Ms. Davis has suffered a number of losses including the death of her mother when she was young and the recent sudden death of her 54 year old sister due to a brain aneuryism. Both her father and her son died of lung cancer, another son died of a heart attack. Her husband was killed, and her boyfriend had a stroke. She had primary caretaking responsibility for all of these family members during their illnesses. She is currently taking medication for anxiety and depression and has frequent crying spells.

Ms. Davis was dissatisfied with her mammogram experience since she was forced to wait a long period at the clinic and felt that she was treated unprofessionally by the clinic staff. She was told that her mammogram was abnormal and scheduled for a repeat mammogram in three months. She doubts that she will go.

Mrs. Ramirez (Mammography)

Mrs. Ramirez is a 57 year old woman from Latin America. She emigrated to the United States in 1986.   She speaks little English. She goes regularly to the Hispanic center for tutoring and is very eager to learn English. She lives with her husband and two of her five daughters. Mrs. Ramirez' mother died recently and she was unable to go back for the funeral. She is very sad about this. She is not sure about the cause of her death. Mrs. Ramirez' only experience with cancer was with the mother of a close friend. She explained that her friend's mother was fine until she had surgery. She believes that something went wrong and the cancer spread. She died a few months later.

Mrs. Ramirez recently had a mammogram and clinical breast exam. She was very uncomfortable with the whole process. She only stayed because she had come with a group from the Hispanic Center who had signed up for the Breast Care Program. After the mammogram she was told that there is a need for more diagnostic tests and was given an appointment to come back in two weeks. She is embarrassed with having to "expose" her breasts, even to a woman, and since she is feeling fine she is not sure she will keep her appointment.

Ms. Chavez (Cervical)

Ms. Chavez is a 41 year old woman with a finding of a high grade cervical lesion (HSIL) from her PAP test.   She is also being seen in the HIV clinic (case manager would not know or talk about

this unless patient discloses to her.) She has just changed jobs and is in a probationary period, after which her health insurance begins. She is concerned about the costs of follow-up procedures and worried about being terminated from health insurance because of different medical problems. She has abdominal pain and wonders if that is caused by her condition(s). She is bi-lingual, but more comfortable talking in Spanish.

Ms. Smith (Cervical)

Ms. Smith is a 27 year old African-American woman. She has just had a baby and needs to return for a post-partum check-up and have a PAP done then. She had an abnormal PAP prior to becoming pregnant, but because of her pregnancy no further tests or procedures were done. She has one other daughter who is in first grade. Ms. Smith is worried about child care, transportation (she does not drive), and the likelihood that she will be moving soon. She is thinking she would prefer to go someplace else to get her post-partum care.

CASE EXAMPLES FOR ROLE PLAY/DISCUSSION: SYSTEMS NAVIGATION PROBLEMS

Case #1

45 year old Latina woman had an abnormal mammogram and was scheduled for an ultrasound guided core biopsy. According to radiology, the patient had failed 3 appointments for the biopsy. Per protocol after three failed appointments, radiology will send the patient back to the referring clinic and the clinic would need to make a new referral to radiology. According to the patient, she had a biopsy but she was unclear where it was performed. The radiology clerk had no record of any biopsy performed and the online medical system Compucare did not indicate any procedure. There are four possible areas to receive a biopsy which are the following: in radiology outpatient, FNA clinic, Women's Hospital Breast clinic or Tumor Surgery clinic. Patient states she is waiting for the results of the procedure she describes as a biopsy. In the meantime, the patient has child care problems creating another barrier for follow-up. At this point the patient is frustrated and she is contemplating whether it is worth coming back to the clinic.

Case #2

33 year old Latina patient had an abnormal PAP smear screening and had a dilation and curettage (D&C). According to the patient she was told that if she did not receive any notice by mail that results turned out normal. According to the cytology report the results came back abnormal with a high grade lesion indicating a need for further diagnostic testing. Per clinic protocol if a patient has a high grade lesion, the clinic contacts the patient by phone. In addition to the confusion over the patient's results, the patient is concerned over the cost of the procedure and she is unsure as to whether her Ability to Pay (ATP) has expired.

Case #3

43 year old Spanish speaking monolingual Latina patient had an abnormal PAP smear screening and returned for her results within three weeks. The result of the patient's biopsy was negative; however, the patient needed a repeat PAP screening. Results indicated a swollen cervix, and the patient was scheduled for a 3-month follow-up. A month later the patient complained of symptoms similar to those of an STD and feared she was infected. The patient has had a history of treatment for STD's and plans to schedule for an earlier appointment. The patient tried calling the clinic, and continues to be disconnected or placed on hold for a long time. The patient states she is frustrated and concerned over her symptoms and does not know what to do.

RESOURCES FOR INFORMATION

American Cancer Society   **1-800-227-2345**

Breast Cancer Early Detection Program (BCEDP)   **1-800-511-2300**

NCI Cancer Information Service   **1-800-4-CANCER**

CancerCare & Cancer Care Counseling Line   **1-800-813-4673**

National Coalition for Cancer Survivorship   **1-800-937-6227**

National Association of Breast Cancer Organizations (NABCO)
9 East 37th Street, 10th Floor
New York, NY 10016

Susan G. Komen Breast Cancer Foundation   **1-800-462-9273**
5005 LBJ Freeway, Suite 730
Dallas, TX 75244

Y-ME   **1-800-221-2141**
National Breast Cancer Support Group
212 West Van Buren Street
Chicago, IL 60607

Center for Cervical Health   **732-255-1132**
PO Box 1209
Toms River, NJ 08753

Vulvar Pain Foundation   **336-226-0704**
Post Office Drawer 177
Graham, NC 27253

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SAFe TRAINING PRE-TEST

Name: _____   **Date: _____**

Please answer each question below by circling the letter of the correct response. Be sure to answer each question, even if it means that you are making your best guess.

Which of the following are risk factors for poorer adherence to follow-up recommendations following an abnormal screening mammogram or PAP?

1. Culturally influence health beliefs
    a) True   b) False

2. Having other significant health problems
    a) True   b) False

3. Size of family
    a) True   b) False

4. Type of insurance
    a) True   b) False

5. National cancer statistics show that approximately how many women die annually from breast cancer?
    a) 10,000   b) 40,000   c) 250,000   d) 1,000,000

6. When a woman needs a follow-up mammogram after the initial screening mammogram this usually means there is a problem which is cancer.
    a) True   b) False

7. Hispanic women have higher rates of cervical cancer than non-Hispanic women.
    a) True   b) False

8. A PAP smear shows abnormal changes in cells of the cervix that are at early stage. This can be treated, but does not prevent cancer of the cervix.
    a) True   b) False

9. Culturally competent case management means treating every woman the same way, period.
    a) True   b) False

10. Screening mammograms often show lumps that are *benign.* What does this term mean?
    a) Harmless   b) Painless   c) Not cancerous   d) Not needing treatment

11. If a woman has been told that she has a lump in her breast and a biopsy is needed, there is a high likelihood (more than 50% chance) that she has a maglignancy.
    a) True   b) False

12. Empowerment practice in case management refers to decreasing the physician's or other health care provider's power so that the patient has more power.
    a) True   b) False

13. Following an abnormal PAP test, a physician may perform a procedure to further examine the vagina and cervix. What is this procedure called?
    a) D&C   b) Hysterectomy   c) Endoscopy   d) Colposcopy

14. A mammogram is an X-Ray.
    a) True   b) False

15. Rates of death from cervical cancer have decreased slightly since the introduction of the PAP test.
    a) True   b) False

16. Dysplasia is another term for cervical cancer.
    a) True   b) False

17. Which of the following is a possible recommendation for follow-up testing for abnormal mammography?
    a) repeat mammogram b) sonogram   c) biopsy   d) a,b,&c   e) b&c only

18. The generally supposed cause of almost all of the most common form of cervical cancers is through sexual transmission of a virus.
    a) True   b) False

19. African-American women have a lower death rate from breast cancer than do White women.
    a) True   b) False

SAFe TRAINING POST-TEST

Name: _____   **Date: _____**

Please answer each question below by circling the letter of the correct response. Be sure to answer each question, even if it means that you are making your best guess.

1. In SAFe case management, a woman who identifies several environmental barriers that could interfere with her medical follow-up would be assigned to which level of service ?
    a) Level I   b) Level II   c) Level III   4) Level IV

    Which of the following are risk factors for poorer adherence to follow-up recommendations?
2. Culturally incomprehensible care
    a) True   b) False

3. Having other significant health problems
    a) True   b) False

4. Type of insurance
    a) True   b) False

5. Having a job
    a)   b) False

6. National cancer statistics show that approximately how many women die annually from breast cancer?
    a) 1,000,000   b) 250,000   c) 40,000   d) 10,000

7. Which of the following is **not** a good idea when trying to establish rapport on the telephone?
    a)   Identify who you are and state the purpose of your call
    b)   Keep your message simple
    c)   Act friendly and casual
    d)   Acknowledge that you don't know the answer to a question you are asked

8. When a woman needs a follow-up mammogram after the initial screening mammogram this usually means there is a problem which is cancer.
    a) True   b) False

9. Hispanic women have higher rates of cervical cancer than non-Hispanic women.
    a) True   b) False

10. The generally supposed cause of almost all of the most common form of cervical cancers is through sexual transmission of a virus.
    a) True   b) False

11. A PAP smear shows abnormal changes in cells of the cervix that are at an early stage. This can be treated but does not prevent cancer of the cervix.
    a) True   b) False

    In making a referral for a service or resource for a woman, it is important to do which of the following?

12. Make a referral for a specific problem regardless of whether the woman agrees she want help with the problem.
    a) True   b) False

13. Let a woman tell you about her past negative experiences using a service or resource.
    a) True   b) False

14. Whenever possible, have a woman make her own arrangements for the service or resource, assuming as much responsibility as she can.

a) True   b) False

15. For many kinds of problems, consider informal resources as a source of assistance before deciding on a formal referral to an agency.
    a) True   b) False

16. SAFe case management provides exactly the same service to every woman for the duration of her time in the program.
    a) True   b) False

17. If a woman has been told that she has a lump in her breast and a biopsy is needed, there is a high likelihood (more than 50% chance) that she has a malignancy.
    a) True   b) False

18. Dysplasia is another term for cervical cancer.
    a) True   b) False

19. Culturally competent case management means treating every woman the same way, period.
    a) True   b) False

20. SAFe case managers do sex education and counseling in some cases.
    a) True   b) False

TRAINING TESTS ANSWER SHEET

Pre-test

1. a
2. a
3. b
4. b
5. b
6. b
7. a
8. b
9. b
10. c
11. b
12. b
13. d
14. a
15. b
16. b
17. d
18. a
19. b

Post-test

1. b
2. a
3. a
4. b
5. b
6. c
7. c
8. b
9. a
10. a
11. b
12. b
13. a
14. a
15. a
16. b
17. b
18. b
19. b
20. a

Clinical Specialist Training Supplement

PURPOSE AND GOALS

The Clinical Specialist Training supplement addresses key issues in the Level III intervention provided by the mental health clinical specialist to women with special needs. It provides guidance and additional resources for the MSW so that clinical services conform to the overall SAFe case management goals.   The clinical specialist will need to receive SAFe training and thoroughly review the complete **Training Manual and Service Manual** as well. SAFe's services, regardless of the level or plan, are all provided from the same culturally competent and empowerment practice base. They are also provided consistently according to protocols, targeted to immediate problems interfering with adherence, and delivered in a cost-conscious manner. When MSW services are provided on a contract basis it is especially important to be sure the clinician is fully oriented to the overall SAFe approach.

The supplement provides information so that the MSW will:

- Understand the criteria and circumstances that trigger a referral from the case manager and how to engage the patient
- Accurately complete diagnostic assessment for depression and other mental disorders
- Provide mental health services according to protocol
- Provide accountable services

REFERRAL FROM THE CASE MANAGER

Criteria for Level III Services

There are specific circumstances that trigger a referral to the MSW. These are 1) a depression screening score in the severe range at initial contact; 2) a diagnosis of cancer; and 3) serious psychosocial stress. These criteria should be reviewed in the **Service Manual,** p.   The case manager initiates a referral to the MSW after the initial contact or after any subsequent contact if any of these circumstances exist. Each category of need is briefly discussed below.

Serious Psychosocial Stress

This is based on the judgment of the case manager. Examples of circumstances that might lead to referral are domestic violence or other serious family conflict, child or elder abuse, and persistent non-adherence in spite of the case manager's efforts. The case manager should consult with the MSW if there is a question about the need for referral. The MSW may elect to provide consultation and suggestions to the case manager first, before accepting a formal referral.

Diagnosis of Cancer

A diagnosis of cancer is one of the criteria for assignment to Level III. SAFe does not assume that a cancer diagnosis, in and of itself, means a woman must have clinical intervention. However, the MSW assesses the patient's coping capacity and level of emotional distress in response to the diagnosis. The MSW also provides information and a referral to psychosocial cancer support services that are available through the site's social work department, or in the community. In the event of co-

existing mental disorder, the MSW follows the mental health protocol discussed below.

Depression and anxiety

Clinical depression and anxiety are mental disorders that can seriously interfere with normal functioning. They are also, in most cases, very treatable. Correct identification of clinical depression and anxiety, and their timely treatment is a key clinical responsibility. It is important to differentiate clinical depression from low morale, general discouragement, "the blues," or what individuals commonly call "being depressed." The women you are trying to help often have difficult lives, overwhelming problems, or circumstances that are, to say the least, "depressing." However, some women, in addition, will be struggling with clinical depression, adding on yet another difficulty. The PHQ is designed to distinguish women with such clinical syndromes. In the same way, anxiety at the clinical level (symptoms reaching diagnostic criteria) is different than the normal feelings of anxiety that accompany upsetting news or circumstances.

Resistance to the Referral

Earlier we discussed several ways for the patient guide to deal with the issue of referring a woman who meets criteria for Level III service to the social worker. Nevertheless, some women, while they have agreed to the call, may be reluctant, skeptical, or even negative at the time the MSW calls. Here we review several key points about handling "resistance." It is critical to understand that resistance can be dealt with and successfully dispelled in many cases. This is part of the work of the first MSW contact.

Tips on Dealing with a Resistant Client

- **Ask client for her perspective of the social work role and clarify any misconceptions.**

- **Recognize and normalize any feelings of ambivalence and fear about speaking with a professional. Discuss her feelings further.**

- **Describe for the woman the benefits she would receive from speaking with the clinical social worker at no charge.**

- **Discuss the process of telephone counseling and how it could be more convenient from the woman's perspective.**

- **Acknowledge the woman's feeling of being overwhelmed by life stressors (and remember that "counseling" can feel like another demand).**

- **Reemphasize the importance of her health and those who depend on her to be healthy.**

- **Reemphasize privacy and confidentiality.**

- **After trying several techniques to encourage a woman to engage in counseling, the MSW may need to acknowledge the woman's lack of interest in answering questions or participating.**

ASSESSMENT FOR DEPRESSION AND ANXIETY AND SEVERE PSYCHOSOCIAL STRESS

The risk assessment form in the initial telephone protocol includes a screen for psychological distress, as discussed earlier. Criteria for referral to the clinical social worker is an initial score of 10 or more on the PHQ-9 depression module and/or14 or above on the BSI items. (Content below includes material from the IMPACT Collaborative Primary Care Depression Trial for Older Adults.) (http://impact-uw.org).

PHQ

For all women meeting the psychological distress criteria for referral to Level III, or presenting on contact with symptoms of depression and/or anxiety, the clinical social worker conducts a criterion-based diagnostic assessment of selected mental disorders, using the **PHQ-9** (Patient Health Questionnaire) of the PRIME-MD. Findings from the clinical assessment suggestive of mental disorder require services according to the protocol discussed in the next section.

Administering the PHQ

The PHQ is a tested patient-based assessment tool designed to quickly elicit information concerning symptoms of the most common mental illnesses. It has been widely used in primary care settings to reliably determine whether symptoms of illness sufficient to satisfy diagnostic criteria are present or not present. In many settings a patient is asked to fill out the questionnaire her/himself. As adapted for SAFe where most of the contact occurs over the phone, the PHQ-9 becomes a series of questions asked by the MSW. The information provided by patients in response to the PHQ has been shown to correspond very well to that elicited in traditional clinical interviews conducted by mental health professionals. While no tool is perfect, there is reason to believe that careful and correct use of the PHQ will provide accurate information about the presence of these mental illnesses.

The original PHQ probes for 5 disorders – mood, anxiety, alcohol, eating, and somatoform, which are the five areas most often seen in primary care. As adapted for SAFE it probes for just two – mood and anxiety.

The MSW may not be accustomed to use of a structured assessment tool, often over the telephone. It is important that you "believe in" the tool if it is to be used effectively.

> **Many clinicians initially worry that the use of structured questions and questionnaires will interfere with building rapport, or are off-putting to clients. Also, because mental illness carries considerable stigma there is concern that women will be embarrassed and defensive when asked to answer direct questions about such "unmentionables." These are valid concerns and need to be taken into consideration as you use the PHQ in your initial contact. What are some of your other hesitations about using this tool?**

Experience has shown that with practice and use clinicians come to be comfortable with the routine use of the PHQ. Here are some key points for its successful administration.

1. As with any task you are trying to achieve in a clinical transaction, the timing of when to administer the PHQ depends on your judgment and sense of the interview. However, <u>when</u> you choose to ask the PHQ questions is really less critical than <u>how</u> you present and administer it.

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2. Remember that dealing in a direct, empathic, but matter-of-fact manner with a woman's emotional distress, just as with any other of her concerns, normalizes this topic, making it safer and more comfortable to talk about. It can be reassuring to a woman that you, at least, are able to hear from her more about how she is actually feeling and functioning. If you are tentative and hesitant about asking the PHQ questions, the woman is likely to respond in the same way.

3. Clarify the purpose of the PHQ in simple, straight-forward language (no jargon), and explain the process involved: it will take about 3 minutes to ask the questions; there are no right or wrong answers; being honest is helpful to the social worker and to herself.

4. Notice carefully that in each of the sections of the PHQ the initial question asks the woman to respond in the context of a specific time frame. As you ask each of the questions in a section it is important to remind the woman of the time frame you are interested in. Look at Question 1. This section elicits information pertaining to mood disorder. The time frame in Question 1 is <u>two weeks</u>. As you ask questions a-I preface each with "In the last two weeks how often have you …" Do the same in the subsequent sections, using the appropriate time frame.

5. In Question 1 the final sub-question asks about thoughts of suicide. Please note that a positive response to this question (regardless of whether a woman responds positively to any others, or reaches threshold for diagnosis) requires further immediate assessment of suicidal potential and immediate intervention as appropriate.

Clinical Psychosocial Assessment

For all other referrals the MSW conducts a clinical psychosocial assessment of a woman and her circumstances. This assessment determines the extent of the difficulty(ies) and its relationship to non-adherence, the likely contributing factors, and the needed actions. The actions may include referral to speciality resources, suggestions for the case manager, and further limited intervention by the clinical specialist/MSW.

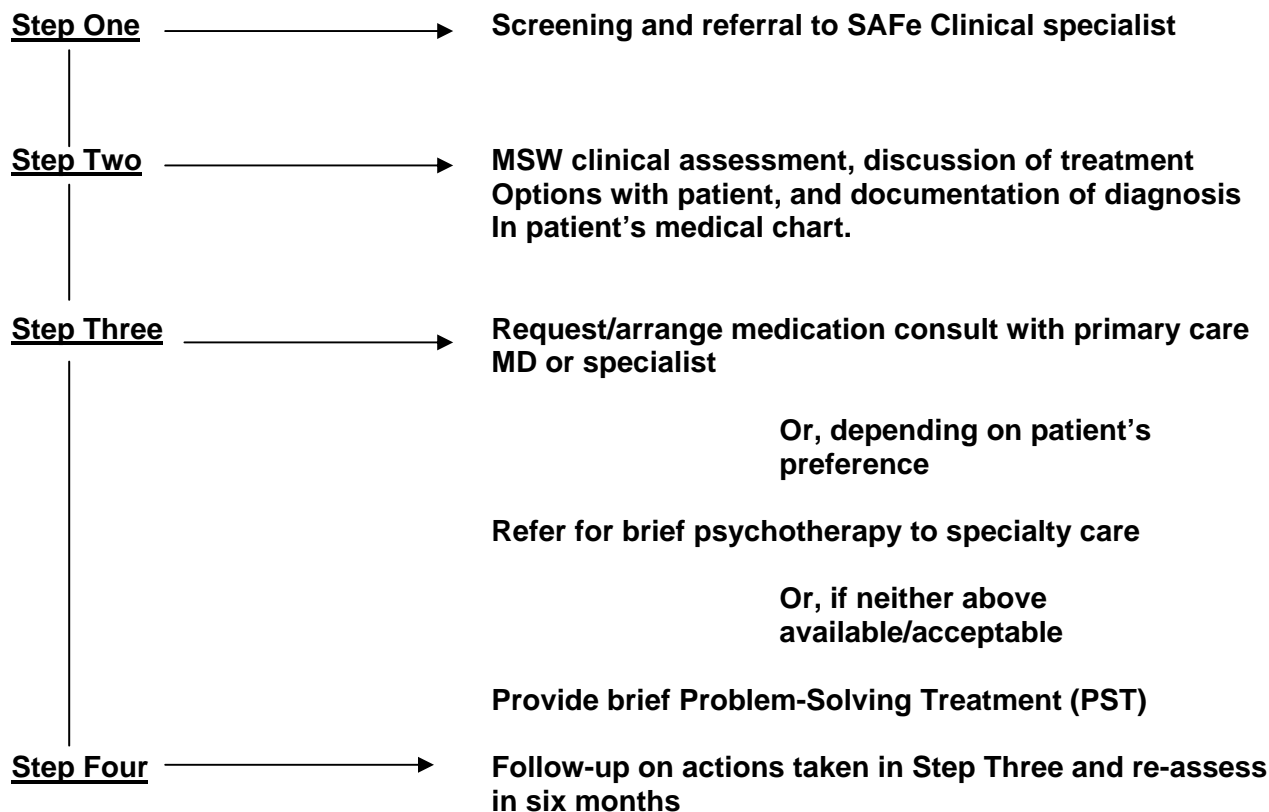**LEVEL III SERVICE PROTOCOLS**

Referral

In general, the primary intervention for women with special needs is to help a woman access the necessary specialty resources through facilitated referral once the clinical assessment is completed. This requires knowledge of specialty resources such as mental health services and cancer support groups, including the nature of their barriers and expectations, and skill in empowering and motivating a woman to avail herself of the resource. It is not assumed that referral is an automatic or straightforward activity in many instances. Please review again the material in the **Training Manual** on making a successful referral.

Often persistence is needed. Follow-up calls to a woman to see if she has made a contact/kept an appointment, combined with additional problem clarification, support and encouragement when she has not are routine. Some women are already involved with other helpers. You want to encourage the woman to discuss concerns with this person as appropriate, and, with her permission, may want to contact the helper directly to share information and reinforce her service needs at this point.

Mental Health Protocol

SAFe has been designed to screen and facilitate treatment for significant mental health problems. Some symptomatic women may already be in care. With the patient's permission the MSW may contact the provider or may empower the woman herself to discuss her persistent symptoms, request adjustment in her medication, more frequent meetings, etc.

A significant percentage of women will not be receiving any care. The mental health service protocol outlined below is for these women. It is derived from extensive research dealing with recognition and treatment of depression in primary health care settings. Additional information supporting the steps of the protocol follows the schematic.

Step One ⟶ **Screening and referral to SAFe Clinical specialist**

Step Two ⟶ **MSW clinical assessment, discussion of treatment Options with patient, and documentation of diagnosis In patient's medical chart.**

Step Three ⟶ **Request/arrange medication consult with primary care MD or specialist**

                                              Or, depending on patient's preference

Refer for brief psychotherapy to specialty care

                                              Or, if neither above available/acceptable

Provide brief Problem-Solving Treatment (PST)

Step Four ⟶ **Follow-up on actions taken in Step Three and re-assess in six months**

A BRIEF GUIDE TO TREATING DEPRESSION IN PRIMARY CARE

(1) SEVEN KEY CHALLENGES IN MANAGING DEPRESSION

1. **Make a diagnosis**.
2. **Educate and recruit** the patient as a partner in treatment.
3. **Start with the best possible treatment**. Avoid minor tranquilizers. Use antidepressants or psychotherapy.
4. **Use an adequate dose**.
5. **Treat long enough**. (Patients often take 6 to 10 weeks to respond.)
6. **Follow outcomes and adjust treatment** as needed. Consider consultation if patient is not improving.
7. **Prevent relapse**. (50% risk after one episode, 70% after two episodes and 90% after three episodes.)

SIGNS AND SYMPTOMS OF DEPRESSION

> • **Depressed mood and/or loss of interest or pleasure**
> *Sadness, tearfulness, guilt, pessimism, sense of failure, self-dislike, dissatisfaction, irritability, social withdrawal, self-harm, apathy, lack of pleasurable activities.*
>
> • **Physical/vegetative *symptoms***
> T*rouble sleeping or sleeping too much (includes early morning awakening), trouble concentrating, decreased energy, decreased sexual interest, loss of appetite, overeating, digestive problems, constipation, bowel irregularities, aches and pains*
>
> • **Physical/vegetative *signs***
> *Disheveled appearance, difficulty sitting still, restlessness, slowed speech, movements and reactions.*

CONDITIONS CHARACTERIZED BY DEPRESSIVE SYMPTOMS

MAJOR DEPRESSION

Diagnostic Criteria for Major Depression (DSM-IV)[<]

Major depression is present when the patient has had **5 of the 9** symptoms listed below for at least two weeks. **One of the symptoms must be either item 1 or 2.**

1. **Depressed mood**	3. Significant change in weight or appetite
OR	4. Insomnia or hypersomnia
2. **Loss of interest or pleasure**	5. Psychomotor agitation or retardation
	6. Fatigue or loss of energy
	7. Feelings of worthlessness or guilt
	8. Impaired concentration or ability to make decisions
	9. Thoughts of suicide or self-harm

[<] **Minor depression** is present when the patient has had **2 to 4** of the 9 symptoms listed above for at least two weeks (*with one of the symptoms being either item 1 or 2).* Minor depressives should be educated and counseled about depression, then re-evaluated in 1 to 3 months, but may not require medication or full-course psychotherapy unless complicating features are present.

DYSTHYMIA

Diagnostic Criteria for *Dysthymia/Chronic Depression* (DSM-IV)

1. Patients with Dysthymia/Chronic Depression are in a depressed mood:
- *for most of the day*
- *for more days than not*
- *for at least 2 years*
- *with lapses lasting not more than 2 months*

2. During periods of depression*, the patient has had two or more of these symptoms:
- *loss of self-esteem*
- *insomnia or hypersomnia*
- *feelings of hopelessness*
- *poor concentration or difficulty making decisions*
- *low energy or fatigue*
- *poor appetite or overeating*

TREATMENT: Dysthymia/Chronic depression can usually be treated the same as major depression, except that the patient may require a full dose of medication for at least *2 years* (maintenance therapy).

- Not including episodes of mania or depression relating to substance abuse. Can coexist with episodes *of major depression*.

MINOR DEPRESSION

Diagnostic Criteria for *Minor Depression* (DSM-IV)

- *The patient has had **2 to 4** of the 9 symptoms listed for major depression for at least two weeks (with one of the symptoms being either item 1 or 2).*

TREATMENT: Patients should be educated and counseled about depression, then re-evaluated in 1 to 3 months, but may not require medication or full-course psychotherapy unless complicating features are present.
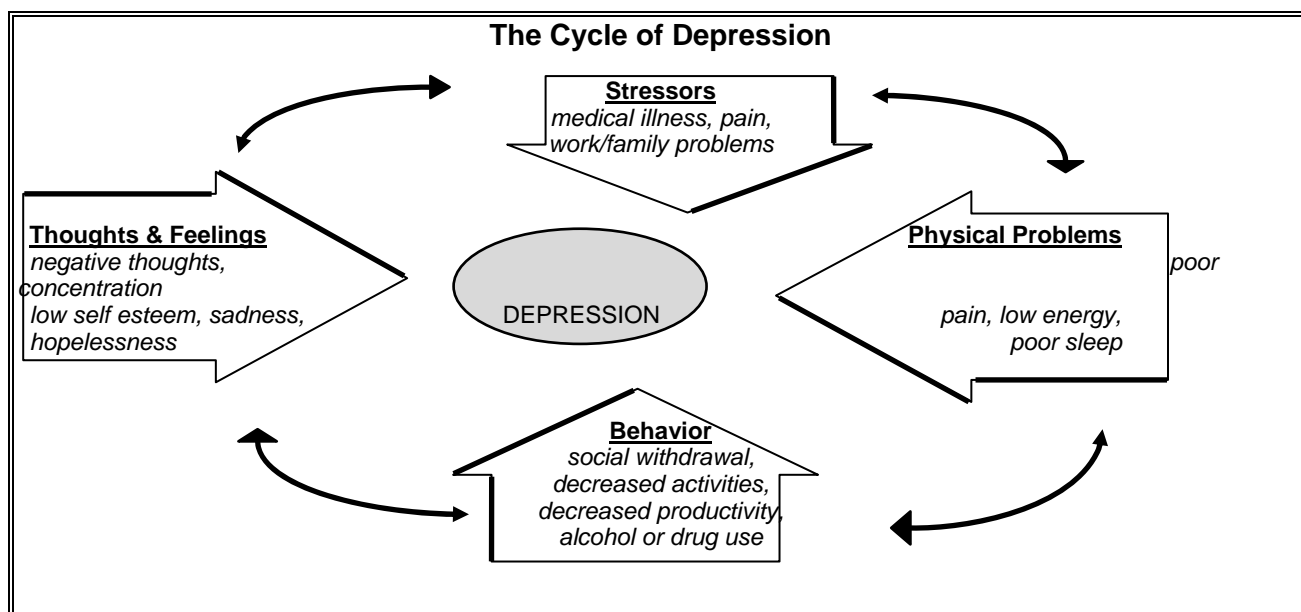

TALKING TO PATIENTS ABOUT DEPRESSION

The cycle of depression model (below) can be helpful in discussing the topic of depression with patients. It points out that depression is a complex syndrome that can involve thoughts and feelings, behaviors, and physical symptoms. While many patients are troubled by negative thoughts and feelings of sadness or hopelessness, others are most aware of physical symptoms such as low energy, poor sleep, poor appetite or overeating, and feeling agitated or 'slowed down'. The cycle of depression model also emphasizes the fact that both life stresses and medical problems can cause a change in certain brain chemicals. This chemical imbalance then results in some of the common symptoms of depression such as sleep and appetite problems, loss of energy, loss of concentration, and chronic pain. The good news is that this downward spiral can be reversed with antidepressant medications or psychotherapy. These treatments can help to improve a person's coping skills, restore normal sleep, and help with pain, fatigue, and poor concentration. When patients feel more rested, it is easier to enjoy one's daily work and activities. Engaging in more pleasant activities gives one a sense of accomplishment and helps one start to think more positively and climb back out of the depth of depression.

In discussing depression with patients, it can be helpful to mention that
- depression is common in primary care
- depression can cause a wide spectrum of symptoms including many physical symptoms

- depression affects the body, behavior, and thoughts
- depression is a medical illness, not a character defect or weakness
- minor tranquilizers (such as benzodiazepines), drugs, and alcohol can make depression worse, not better
- recovery from depression is the rule, not the exception
- the good news is that depression can almost always be treated either with antidepressant medications or with psychotherapy
- there is a high risk of recurrence: 50 % after one episode, 70 % after two episodes, and 90 % after three episodes of major depression.

The Cycle of Depression

Stressors
medical illness, pain, work/family problems

Thoughts & Feelings
negative thoughts, concentration
low self esteem, sadness, hopelessness

DEPRESSION

Physical Problems
poor

pain, low energy, poor sleep

Behavior
social withdrawal, decreased activities, decreased productivity, alcohol or drug use

PATIENT INFORMATION ABOUT ANTIDEPRESSANT MEDICATIONS

How do antidepressants work?

Both life stresses and medical problems can change chemical messengers in the brain that maintain the balance in how you feel emotionally and physically. This chemical imbalance results in some of the common symptoms of depression such as sleep and appetite problems, loss of energy, poor concentration, and greater sensitivity to pain. Antidepressant medications can help restore a normal balance of these chemical messengers, which helps to relieve emotional and physical symptoms.

Antidepressants can take up to 8 weeks to work. It usually takes two to four weeks until people start feeling better emotionally and physically. The improvement may be gradual, and often family members or friends may notice a difference in how you are doing before you do. Your sleep and appetite may improve first, and your mood, energy, and negative thinking may take some more time to improve.

Once you are feeling better, do not stop the medication right away. Your doctor may recommend taking the medication for six to nine months or longer to prevent a relapse of the depression.

How to find an antidepressant that works for you.

Scientific studies show that antidepressant medications do not differ in the percentage of patients that get better. However, different medications are effective for different people, and the

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side effects of the medications differ. Some medications also cost more than others. Your doctor can help you decide which medication may be best for you.

Between 50 and 80 % of patients will get better after 4 to 8 weeks on an antidepressant medication. By working together, you and your doctor can decide whether the medication you started is the right one for you. If you need to switch to another antidepressant because of side effects or because you are not substantially improved, chances are still excellent that you will improve on a second medication.

What about side effects?

Some people may experience side effects when taking antidepressant medications. While these side effects can be annoying, they are rarely dangerous to your health. They usually occur in the first few weeks and then gradually decrease as your body adapts to the medication. Because of these early side effects, patients sometimes feel a little worse before they start getting better and may give up too soon. If you have side effects that are bothering you, discuss these with your doctor or your depression clinical specialist. Your doctor will help you determine if these side effects will decrease over time or if you should decrease or switch your medication.

Some of the side effects that can occur with antidepressants include

- Nausea
- Headaches
- Jitteriness
- Weight gain

- Diarrhea
- Insomnia
- Sedation
- Urinary hesitancy

- dizziness
- rapid heart rate
- temporary difficulty in achieving orgasm

- blurred vision
- dry mouth
- constipation
- *other:_____*
  _____

Remember:
1. Take the medications daily
2. Keep track of side effects and discuss them with your physician**.**
3. Antidepressants are not addicting or habit forming. They do not make people 'high', and they do not lead to serious withdrawal symptoms once you stop them.
4. It may take 2-10 weeks to feel the full benefits of antidepressants.
5. Continue to take the medication even when you feel better.
6. **Don't stop the medications before talking with your primary care provider.**

COMMON QUESTIONS ABOUT TREATMENTS FOR DEPRESSION

Questions about antidepressant medications:

1. **How do antidepressants work?**
   - Antidepressants help restore the correct balance of certain chemicals called **neurotransmitters** in the brain.

2. **My problem is inability to sleep. How can an antidepressant help with this?**
   - In many cases, poor sleep is a by-product of a major depression. Once the depression lifts, sleep often improves as well.
   - Antidepressants can help restore normal sleep, even in people who do not have major depression. They are advantageous over other sleeping pills in that they are not habit-forming, and they usually do not impair concentration or coordination.

3. **I have a problem with pain. How can an antidepressant help with this?**

- Some antidepressants have been shown to be successful (even in the absence of major depression) in a number of pain conditions such as diabetic neuropathy, postherpetic neuralgia, and phantom limb pain.
- Antidepressants may also help restore normal sleep and 'reverse' a vicious cycle of pain and poor sleep.

4. I have low energy and feel tired a lot of the time. How can an antidepressant help with this?

- Low energy and fatigue commonly occur in people with major depression. Once the depression improves, their energy starts to return as well.
- Antidepressants can help restore energy in patients who are depressed. With successful treatment, patients will feel less tired and more able to do their usual activities.

5. I have a lot of stress in my life. How can an antidepressant help with this?

- Life stress can cause or worsen the symptoms of depression. The depression can then worsen the impact of such stressors (such as work stress, family problems, physical disabilities or financial worries) and your ability to cope with them. Treating the depression can help some patients break out of this vicious circle.

6. Are antidepressants addictive?

- **No.** Antidepressants are not habit-forming or addictive. They do not produce a 'high' feeling, but slowly alter the amount of certain chemicals called neurotransmitters in the brain over a number of weeks. Restoring the levels to a more normal balance usually brings the depression under control.
- Some people have been taking antidepressants continually for up to 30 years without any significant (physical or psychological) adverse effects.

7. My problem is anxiety or panic attacks, not depression. How can antidepressants help?

- In many cases, anxiety is a by-product of depression. Once the depression lifts, the anxiety improves as well.
- Some antidepressant medications are also among the most effective medical treatments for anxiety disorders, including panic disorder and generalized anxiety disorder.

8. How long will it take the medications to work?

- It usually takes from one to six weeks for patients to start feeling better. In many cases, sleep and appetite improve first. It may take a little longer for your mood, energy, and negative thinking to improve.
- If the depression has not improved after 4 to 6 weeks, you may need an increase in the dose or a change to another antidepressant.

9. How long will I have to take the medication?

- Once you are completely recovered from your depressive episode, you should stay on the medication for another 6 months to prevent a relapse.
- Some patients who have had previous depressive episodes or are otherwise at high risk for a recurrence should be kept on a 'maintenance' dose of antidepressants for longer periods of time.

10. Are there any dangerous side effects?

- Side effects from antidepressants are usually mild. You should ask your doctor or depression clinical specialist (who will coordinate with your doctor) what to expect and what to do if you have a problem.

- In many cases, your body will get used to the medication and you won't be bothered with the side effect for long. In other cases, your doctor may suggest that you lower the dose, add another medication, or change to another antidepressant. If used properly, there are no dangerous or life-threatening side effects.

11. Is it safe to take antidepressants together with alcohol or other medications?
- In general, antidepressants can safely be taken with other medications. You should let your doctor or depression clinical specialist know exactly which other medications (including over the counter medications) you are taking so that he/she can make sure that there are no problems.
- Antidepressants can increase the sedating effects of alcohol. Be careful to avoid excessive alcohol intake while on these medications.

12. What should I do if I miss the medication one day?
- Don't 'double up' and take the dose you forgot. Just keep taking your medication as prescribed each day.

13. Can I stop the medication once I am feeling better?
- **No**. You would be at high risk for having the depression come back, and may experience some temporary withdrawal symptoms. After one episode of depression, there is a 50 % risk that the depression will return. After two episodes, the risk goes to 70%; and after three episodes, the chances are 90 % that you will have a recurrence if you stop using the medication. In most cases, you should continue the medication for at least 6 months after you and your doctor agree that your recovery is complete.
- **DON'T STOP THE MEDICATION BEFORE DISCUSSING IT WITH YOUR PHYSICIAN OR DEPRESSION CLINICAL SPECIALIST.**

14. Will I get better?
- With adequate treatment, between 50 and 80 % of patients will have a complete recovery.
  - Should you not respond to the first antidepressant treatment you try, there is an excellent chance that you will respond favorably to another medication or to psychotherapy.

QUESTIONS ABOUT PROBLEM SOLVING TREATMENT (PST-PC)

1. What is PST-PC?

Problem-solving treatment – primary care (PST-PC) is a brief form of psychotherapy that teaches people how to solve the problems that are making them depressed. You will meet with your depression clinical specialist for 4-8 weeks, and during that time you will learn seven steps to fix the problems that are bothering you.

2. Four to eight weeks seems awfully short. How can I solve all my problems in so few meetings?

The goal of PST is to teach you how to solve problems on your own. You will not be expected to solve all your problems during this time. But, you will get to solve a few problems. By working on some of your problems in the 4-8 weeks you have with your depression clinical specialist, you will learn to solve all the other problems in your life on your own.

3. Four to eight weeks seems awfully long to learn how to solve problems. Do I have to go to every one of those meetings?

Learning how to solve problems is not easy. You will want to practice the skills you are being taught. Although you do not have to use all 8 meetings, you will want to work with your depression clinical specialist at least 4 times to learn PST.

4. Do I have to tell my DDCS everything?

Most people have a hard time talking about their problems to people they don't know. While it is important to talk about all the major problems that you think are related to your depression, you don't have to talk about every problem you have. Because the goal of PST-PC is to TEACH you how to solve problems on your own, you can learn PST by focusing on any problem you feel comfortable discussing.

5. Do I have to talk about my mother?

Not unless she is currently one of your problems. PST-PC focuses on problems you are having now, not your childhood.

6. Homework? What if I don't do my homework?

We encourage you to practice you new skills outside of the meetings. Try and do your homework! You will not be graded. But, even if you don't finish your homework, plan on coming anyway, we want to see you.

PROBLEM SOLVING TREATMENT FOR PRIMARY CARE (PST-PC)

A full explanation and instructions for brief problem-solving treatment is beyond the scope of this manual. If unfamiliar with this form of therapy, the clinical specialist should consult the following resources:

- Social Problem Solving Therapy: Theory, Research and Practice (1989). Nezu, Nezu and Perri.

- Problem-Solving Therapy: A Social Competence Approach to Clinical Intervention. (1999). D'Zurilla and Nezu.

- A Problem-Solving Approach: Helping Cancer Patients Cope (1998). Nezu, Nezu, Friedman, Faddis and Houts.

COMMUNITY RESOURCES

As discussed above, SAFe's clinical intervention for women with special needs is focused on facilitating referral to appropriate resources whenever possible. It recognizes that this is a skilled clinical function requiring some degree of trust and may take time and effort. It is not an automatic or "paper" process. The SAFe clinician must develop a thorough knowledge of appropriate and accessible resources, including culturally targeted resources when available. Locating specialized resources for cancer information and psychosocial support and for specialized mental health care will be the highest priority.

SAFe case management targets women who are medically underserved, and it is likely that resources are inadequate or not readily available for their mental health care as well. Thus resource location and development is by no means a routine or simple activity. Sources of assistance with payment for medications and treatment will need to be identified as well as the treatment resources themselves.

DOCUMENTATION

Key information and circumstances that must be documented in the patient's medical chart are discussed in the Service Manual. The SAFe clinical specialist providing services on a contract basis will need to negotiate an agreed upon process and procedure for medical charting at the time of accepting the position. If the clinical specialist is an employee of the screening/diagnostic/treatment site, the appropriate documentation protocol of the site should be followed.

In both instances the intent is to provide accountable professional services with adequate communication to other members of the health care team concerning circumstances and information bearing on a woman's health care.

CASE EXAMPLES: MSW LEVEL III

Case #1
Patient is a 51 year old Filipina woman who visited her family in the U.S. During her trip the patient was admitted to the hospital for a leaking heart valve in 1997. Patient decided to stay in the U.S. in order to continue with her heart treatment, leaving behind her husband and children in the Philippines. In 1999 the cardiology clinic referred patient to radiology to acquire a CBE and a mammogram. Patient had an abnormal mammogram with a birad code 5 and will need an excisional needle directed biopsy. According to the doctor the patient has breast cancer possibly stage II. Patient temporarily resides with her sister in XXXX and takes three buses to get to the hospital. Because patient is undocumented she has no insurance and relies upon her sister for financial assistance.

Case #2
Patient is a 64 year old Mexican Spanish speaking woman with multiple health problems such as arthritis, hypertension and diabetes. Patient had an abnormal mammogram with a birad code 4 and needs an ultrasound core biopsy. The patient scored high on the BSI indicating some degree of depression. Ten years ago the patient received mental health treatment for depression. The patient temporarily lives with her daughter and her daughter's family. Patient has a history of moving from one location to another, residing with family, and plans on leaving her daughter's home without any arrangement set. The patient recently began collecting early Social Security disbursements. Patient has no insurance and has problems with transportation.

Case #3
Patient is a 50 year old Mexican bilingual woman who had an abnormal pap smear screening. Patient had a low grade lesion and needed a repeat pap smear and possibly a colposcopy. Patient has a history of sexual and physical abuse as a victim of domestic violence. Patient divorced a few years ago and has a restraining order against the perpetrator. However, she fears her ex-husband will someday come after her. Patient scored high on the BSI anxiety questions. Patient does not have insurance and resides with her daughter.

Case #4
Patient is a 23 year old Mexican monolingual Spanish speaking woman. Patient had an abnormal pap smear screening and was diagnosed with HPV (Human papillomavirus). Patient had a LEEP biopsy procedure and needs to return for results and possibly a repeat pap smear. Patient recently married and she is recognizing problems within the relationship. Patient quit her job in order to become a full-time housewife. Patient and her husband are attending the infertility clinic for testing in order to understand why they are unable to conceive children. Patient is also undergoing blood testing to determine whether she has TB. Patient and her husband are also being evicted from their apartment.