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5.0 SCREENING SERVICES

The importance of routine screening/rescreening is emphasized at every opportunity. Clinical management strategies for Pap test and pelvic exam rescreening is based on consultation with the IBCCP medical advisory consultants and in consideration of the standards established by the American Society for Colposcopy and Cervical Pathology (http://www.asccp.org) and the American Congress of Obstetricians and Gynecologists (http://www.acog.org/) and CDC recommendations.

Services provided to IBCCP clients will depend on the reason for the clinical evaluation. Some clients may only need breast or cervical services; however, the majority of clients will need both services. The following components must be offered to all clients at enrollment and at time of rescreen based on IBCCP protocol:

Client education related to breast and cervical health with emphasis on:

A.) Breast self-awareness; Women should be encouraged to know their breast and seek medical attention if any breast changes are noted. There is insufficient evidence to recommend for or against the practice of Breast Self Exam (BSE) on an individual level. If a woman wishes to be taught BSE, she must be informed of the potential risks and benefits.

B.) Pelvic examination based on an interval screening cycle;

C.) Pap test based on an interval screening cycle;

D.) Referral for screening mammogram, if appropriate; and

E.) Referral for diagnostic services, if appropriate.

If a client refuses clinical services, this must be clearly documented in the IBCCP client record. The overall objective of the BCCP Program is for the client to receive comprehensive services, including both breast and cervical cancer screenings. However, if a client refuses a service (mammogram or Pap test) she is allowed to remain in the Program. The clinical patient navigator (case manager) is to continue to educate about the importance of total care and encourage the client to receive all services offered.

5.1 BREAST CANCER SCREENING

Excluding cancers of the skin, breast cancer is the most common cancer diagnosed among women. Approximately one out of every eight women in the United States will
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develop breast cancer sometime during her lifetime. Death rates for breast cancer have steadily decreased in women since 1989, with larger decreases in women younger than 50 (a decrease of 3.2% per year) than in those 50 and older (1.8% per year). The decrease in breast cancer death rates represents progress due to earlier detection, improved treatment and in the more recent time period, decreased incidence. Approximately 77% of the women diagnosed with breast cancer are over age 50. Breast cancer is the second leading cause of cancer deaths in women between the ages of 35 and 54. In 2015, it is estimated that 231,840 new cases of invasive breast cancer will be diagnosed and 40,730 women will die from breast cancer.

The two most significant risk factors associated with the risk of developing breast cancer are being female and getting older. Of the women diagnosed with breast cancer, many have no identifiable risk factors other than age and gender.

EARLY DETECTION IS THE BEST PROTECTION AGAINST BREAST CANCER.

The cause of breast cancer is unknown. Because the source is not yet understood, the disease cannot be prevented. Based on the current knowledge of genetics, about 5 – 10% of women with breast cancer have a hereditary form of the disease. These women have a higher risk of developing breast cancer at a younger age (before menopause), and they often have multiple family members with the disease.

Early detection of breast cancer greatly improves the chances of survival. The 5-year relative survival rate is 99% in women whose breast cancer is detected while the disease is localized. The 5-year relative survival rate drops to only 25% with distant metastasis. Therefore, early detection of breast cancer through clinical breast examination (CBE), breast self examination (BSE), and mammography are all important to improve the survival rate.

5.2 BREAST CANCER SCREENING GUIDELINES

CDC has teamed with Medscape™ from WebMD™ to develop an online continuing medical education (CME) program called Follow Up of Abnormal Clinical and Imaging Findings of the Breast: Five Self-Study Modules for Primary Care Clinicians. The five self-directed, interactive training modules are designed to educate clinicians on providing appropriate and timely care to women with early signs of breast cancer, and to train physicians on the latest evidence, protocols, and guidelines around detecting breast cancer.

These modules were developed by CDC’s Division of Cancer Prevention and Control (DCPC), endorsed by the American Congress of Obstetricians and Gynecologists, and
ACKNOWLEDGED BY THE UNITED STATES FOOD AND DRUG ADMINISTRATION. THE MODULES WERE EDITED AND CERTIFIED FOR CME CREDIT BY MEDSCAPE.

THE CURRICULUM IS AVAILABLE TO REGISTERED MEDSCAPE MEMBERS AT HTTP://WWW.MEDSCAPE.COM/EDITORIAL/PUBLIC/BREASTCANCER-CDC.

CONTRACTED LEAD AGENCIES ARE TO PROVIDE ALL MEDICAL PROVIDERS WITH COPIES OF THE RESOURCE LISTED ABOVE. THE SELF-STUDY MANUAL IS INCLUDED IN APPENDIX J. ALSO INCLUDED IN APPENDIX J ARE NEW GUIDELINES FOR CLINICAL BREAST EXAMS (CBE).

5.3 GUIDELINES FOR BREAST CANCER FOLLOW-UP

IBCCP follows the American Society of Clinical Oncology (ASCO) guidelines on postoperative surveillance for the detection of recurrent breast cancer. Recommendations for the post treatment for breast cancer clients who are asymptomatic after primary curative therapy include:

A.) History and physical examination on the following schedule:
   • Every 6 months for 3 years
   • Then annually

B.) Client education regarding symptoms of reoccurrence

C.) Breast self-examination monthly

D.) Mammography yearly
   • Following **lumpectomy** (affected and unaffected breasts)
   • Following **reconstructive surgery** (unaffected breast)
     ▪ Because some reconstructive surgeries allow a woman to retain her natural nipples and the tissues under the skin, women should check with their physicians regarding mammography of the affected breast since enough breast tissue may be retained to warrant mammography of the affected breast.
   • Following **simple, modified radical or radical mastectomy**
     ▪ While some mammography centers/radiologists recommend routine imaging of the affected breast(s) after simple, modified radical or radical mastectomy with or without breast reconstruction, statistical evidence is limited to support its benefit. Most physicians do not recommend screening mammography on women who have undergone mastectomies. Clients should consult...
with their physicians regarding mammography of the affected breast(s).

E.) Pelvic examination yearly

F.) Assessment of Bone Health
   - Chemotherapy induced menopause is a significant, long-term side effect of adjuvant cancer treatment that is associated with an increased risk of osteoporosis.

The following are not recommended for routine breast cancer surveillance:

A.) Routine blood work (CBC, liver or kidney function tests)
B.) Routine chest x-ray
C.) Routine bone scan, CT scans, liver ultrasound, or other imaging
D.) Tumor markers, including CA 15-3, CA27-29 or CEA
E.) Breast MRI
F.) PET scans

The risk of breast cancer reoccurrence continues through 15 years after primary treatment and beyond. Continuity of care for breast cancer clients is recommended and should be performed by a physician experienced in the surveillance of cancer clients and in breast examination, including the examination of the irradiated breasts.

5.4 CERVICAL CANCER SCREENING

An estimated 12,900 cases of invasive cervical cancer are expected to be diagnosed in 2015. Incidence rates have decreased steadily over the past several decades in both white and African American women due to prevention and early detection as a result of screening, although this trend has begun to taper off in young white women. As Pap screening has become more prevalent, pre-invasive lesions of the cervix are detected far more frequently than invasive cancer. An estimated 4,100 cervical cancer deaths are expected in 2015.

Cervical cancer risk is closely linked to sexual behavior and to sexually transmitted infections with certain types of human papillomavirus (HPV). Women who have first intercourse at an early age, multiple sexual partners, or partners who have had multiple sexual partners are at increased risk of developing the disease. Other risk factors include cigarette smoking and low socioeconomic status.

Human papillomavirus is a small DNA virus associated with the development of cervical cancer. Most women with cervical HPV infection will not develop cervical cancer; however, because HPV sequences are found in more than 99% of all cervical cancers, HPV infection is viewed as a necessary factor in the malignant transformation to cervical cancer. HPV-16 and 18 account for approximately 70% of all cervical cancers, but the distribution of tumor histology is correlated with HPV type: HPV-16 DNA is more commonly found in squamous cell carcinomas, and HPV-18 DNA is more commonly found in adenocarcinomas.

The U.S. Food and Drug Administration approved, for females aged 9-26, a quadrivalent HPV vaccine that prevents cervical cancer caused by HPV-16 and 18. For more information go to http://www.cdc.gov/std/hpv/STDFact-HPV-vaccine-hcp.htm.

**EARLY DETECTION IS THE BEST PROTECTION AGAINST CERVICAL CANCER.**

Virtually all cervical cancer deaths are preventable by early detection and appropriate intervention and follow-up. Detection and treatment of precancerous cervical lesions identified by Pap tests can actually prevent invasive cervical cancer. Almost half of the clients (47%) are diagnosed when the cancer is localized. The five year survival rate decreases when it is not at its localized stages as shown below:

- Confined to the cervix and has a 5-year-survival rate of 91 percent.
- Regional stage disease has a 5-year-survival rate of 57 percent.
- Distant stage disease has a 5-year-survival rate of 16 percent.

The widespread implementation of preventative services for the early detection of this disease has been associated with substantial reductions in morbidity and mortality. As screening has become more common, pre-invasive lesions of the cervix are detected far more frequently than invasive cancer. The Pap test is the most widely used cervical cancer screening method.
5.5 CERVICAL CANCER SCREENING GUIDELINES

Historically, there were several different recommendations from national, professional and governmental organizations regarding the frequency of use and the age at which to begin Pap testing. In March 2012, new cervical guidelines were released which were developed in a combined effort by the American Cancer Society (ACS), the American Society of Clinical Pathology (ASCP) and the American Society for Colposcopy and Cervical Pathology (ASCCP). The new guidelines have also been adopted by the American Congress of Obstetricians and Gynecologists (ACOG). Importantly, the guidelines developed by the ACS and the ASCCP have been, for the most part, harmonized with the cervical cancer screening guidelines that were formally released by the U.S. Preventive Services Task Force (USPSTF). This is the first time in several decades that all of the organizations involved with cervical cancer prevention in the U.S. have endorsed essentially equivalent guidelines.

The appropriate management of women with histological diagnosed cervical abnormalities is an important component of cervical cancer prevention programs. In March 2013, ASCCP released the new 2012 consensus guidelines for management of abnormal cervical cancer screening tests and CIN/AIS. The new guidelines and algorithms are published in the article 2012 Updated Consensus Guidelines for the Management of Abnormal Cervical Cancer Screening Tests and Cancer Precursors in the Journal of Lower Genital Tract Disease. This article and the algorithms are available in Appendix J.

5.6 PROVISION OF PAP TESTS AND PELVIC EXAMS

Conventional Pap Test and Liquid Based Pap Test

Effective July 2012, IBCCP will reimburse for HPV co-testing, the combination of cytology and human papillomavirus (HPV) testing every 5 years for women 35-64. Women should receive either Pap testing alone every 3 years or Pap testing with HPV testing every 5 years. Co-testing at 5-year intervals provides a cancer risk similar to or lower than screening with cytology alone at 3-year intervals. Co-testing at 5-year intervals is the preferred method for women ages 30-64 however; Pap testing alone every 3 years is acceptable for this age group regardless of testing modality. CDC understands that it will take time to educate providers and clients on these new screening recommendations. All Lead Agencies and providers must provide the option of Pap testing every 3 years or co-testing every 5 years (for women ages 35-64).
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Exceptions to Three and Five-Year Interval

A.) Women who are considered high risk (e.g., history of cervical cancer, exposed to diethylstilbestrol (DES) in utero, immunocompromised due to HIV infection, organ transplant or any other immunocompromised disease).

B.) Women previously treated for CIN2, CIN3, or cervical cancer. See Section 5.7 Guidelines for Cervical Cancer Follow-Up.

C.) Unsatisfactory Pap tests include those that are rejected (not processed) generally because of insufficient labeling, slide breakage, or leakage of liquid specimens. Most unsatisfactory Paps are processed and fully evaluated by the laboratory but meet morphologic criteria for an unsatisfactory specimen (Appendix J).

1.) **Conventional Pap Tests** can be rendered unsatisfactory by obscuring blood, inflammation, or other processes.

2.) **Liquid-Based Cytology** is done more frequently and can be controlled for most obscuring factors in processing, unsatisfactory results arise largely from insufficient squamous cells.

D.) Cytology Negative for Intraepithelial Malignancy but EC/TZ Absent/Insufficient Please follow this algorithm when monitoring women with this exception to the three and five-year interval.
Guidelines for women who have a Pap test that is negative for cervical intraepithelial neoplasia (CIN) or malignancy, but endometrial cells are present

A.) In pre-menopausal women, normal endometrial cells on a Pap test do not indicate an endometrial abnormality, and there is no need for further evaluation. If these cells are seen on the Pap test of a woman who is still menstruating, and the report indicates that the cells are benign, this should be considered normal and routine screening should continue.

B.) In post-menopausal women, showing endometrial cells on a Pap test is abnormal and needs further follow up with endometrial biopsy. Because these women are post-menopausal, they should not be shedding endometrial cells. Therefore, this finding would be of concern and an endometrial biopsy should be considered.

**HPV Testing**

- HPV high risk testing is allowed and reimbursed by IBCCP per ASCCP guidelines.
- IBCCP **does not** reimburse for HPV DNA Typing as referenced in the ASCCP algorithm for Management of Women ≥ Age 30, who are Cytology Negative, but HPV Positive. Note: HPV DNA typing is different from HPV high risk testing.
Use of Automated Screening Technologies for Quality Assurance

Funds may not be used to reimburse automated technologies when they are used as a secondary assessment of Pap testing for quality assurance purposes. These quality assurance costs are included in the pricing of tests and are paid by the cytopathology laboratories.

Pap Test Rescreening Process Using Every Three or Five Year Schedule

A.) When a client has been identified as due for rescreening services regardless of the screening technique used, do one of the following 2 activities:

1.) Go to SV06 and scroll through the entire list of services to determine whether the client had a normal Pap test only or had a combination of Pap test and HPV testing.

2.) Go through the clients’ medical record to determine whether a normal negative or benign Pap test has been completed or a combination of Pap test and HPV testing.

Record this information based on local agency policy and note when the next Pap test is due based on the 3 or 5-year schedule. The location in the client chart for recording this information needs to be predetermined by the agency based on the flow of reports through the office. The front of the client record is one suggestion. Some agencies have developed a check sheet with space allotted to fill in and easily find this information. Other agencies have chosen to mark this information at the top of the Client Eligibility Determination Form.

B.) Clients need to be kept informed of the services they are eligible for through the Program. They need to be reassured during the years that they are not eligible for a Pap test and pelvic exam that they can contact the agency if there is a change in their condition.

C.) Medical providers are to be informed when making the client’s appointment that Pap test, pelvic exam or mammography services are not needed and will not be reimbursed during the current screening cycle. Reinforce that the appropriate ACOG, USPSTF, and ACS Screening Guidelines are supported by CDC. Medical providers need to be reassured that if the client expresses concern about her health or indicates a change in her health status that a request for these services would be considered.
5.7 GUIDELINES FOR CERVICAL CANCER FOLLOW-UP

IBCCP follows the standards established by the American Society for Colposcopy and Cervical Pathology (http://www.asccp.org) and recommendations from the IBCCP Medical Advisors regarding post treatment surveillance for the detection of recurrent cervical cancer in women who have NOT had a hysterectomy.

Women with a History of Cervical Intraepithelial Neoplasia (CIN2, 3), Adenocarcinoma in Situ or Cervical Cancer

Women treated in the past for CIN2 or higher remain at risk of persistent or recurrent disease for at least 20 years after treatment. Therefore, they should continue to undergo routine age-based screening for 20 years after spontaneous regression or appropriate management of the initial post-treatment surveillance period, even if it requires that screening continue past the age of 65. Please note IBCCP does not pay for screening in women 65 and older, unless they do not qualify for Medicare.

For Women with a History of Cervical Intraepithelial Neoplasia (CIN2, CIN3, or CIN2,3)

Acceptable post treatment management following cryocautery, LEEP or conization with CLEAR MARGINS, includes one of the following:

1. Co-testing at 12 months and 24 months
   • If both co-tests are negative, retest in 3 years
   • If any test is abnormal, schedule colposcopy with endocervical sampling
   • If all tests are negative, perform routine screening for at least 20 years

POSITIVE MARGINS - identified at the time of a diagnostic excisional procedure or during an endocervical sampling obtained immediately after the procedure, require reassessment using cytology and endocervical sampling at 4-6 months after treatment is completed. Performing a repeat diagnostic excisional procedure is acceptable. Hysterectomy is acceptable in some cases when fertility is completed. A repeat diagnostic excision or hysterectomy is acceptable for women with a histological diagnosis of recurrent or persistent CIN2, CIN3 or CIN2,3.
For women with Adenocarcinoma in-situ (AIS) or Cervical Cancer:

Hysterectomy is preferred for women who have completed childbearing and have a histologic diagnosis of AIS on a specimen from a diagnostic excisional procedure. Note: IBCCP does not reimburse for a hysterectomy.

Conservative management is acceptable if future fertility is desired.

- **CLEAR MARGINS** – Follow up is only acceptable if the margins are clear when the LEEP/conization is completed. The client should have cytology completed at 6 and 12 months and then annually for 20 years.

- **POSITIVE MARGINS** – If the LEEP/conization shows positive margins, re-excision must be performed if the client wants to avoid hysterectomy. Re-evaluation at 6 months using a combination of cervical cytology, HPV and colposcopy with endocervical sampling is acceptable. Long-term follow-up is recommended for women who do not undergo hysterectomy.

**WOMEN WITH HYSTERECTOMY**

IBCCP funds CANNOT be used to reimburse for cervical cancer screening in women with total hysterectomies (i.e., those without a cervix), unless the hysterectomy was performed because of cervical neoplasia (precursors to cervical cancer) or invasive cancer.

- For women with a history of cervical neoplasia or in situ disease, IBCCP funds can be used to reimburse for routine cervical screening for 20 years post treatment.
  - For a hysterectomy due to confirmed cervical intraepithelial neoplasia (CIN2,3), the ACS/ASCCP/ and American Society of Clinical Pathology (ASCP) recommendations specifically state that following spontaneous regression or appropriate management of CIN2, CIN3 or adenocarcinoma in situ, routine screening should continue for at least 20 years (even if this extends screening past age 65 years for non IBCCP women). Routine screening is co-testing every 5 years or Pap testing alone every 3 years.
For women with a history of invasive cervical cancer, IBCCP funds can be used to reimburse for cervical cancer screening indefinitely as long as they are in good health.

- Women should be screened every six months for a period of five years. Then, annual screening should continue for life (for both Conventional and Liquid Based Cytology) because these women are at risk for vaginal dysplasia.

- For women whom the reason for the hysterectomy or cancer cannot be documented or that there was no neoplasia, IBCCP funds can be used to reimburse for cervical cancer screening. For these women, cervical cancer screening should continue with Pap tests every 3 years or co-testing every 5 years until there is a 10-year history of negative screening results, including the documentation that the Pap tests were technically satisfactory.

The presence of a cervix can be determined with a physical examination. IBCCP funds CAN be used to reimburse for an initial (i.e., pelvic examination) to determine if a woman has a cervix.

5.8 RESCREENING SERVICES

Rescreening services are recommended annually for women over 40 years of age for breast cancer screening; this includes clinical breast examinations and mammograms. Rescreening services for cervical cancer screening are recommended every three years with a Pap test alone or co-testing every 5 years with Pap test and HPV testing in women ages 35-64. For women aged 30-64 years, co-testing with cytology and HPV testing every 5 years is preferred. In women aged 30-64 years, screening with cytology alone every 3 years is acceptable. Annual cervical screening should not be performed if the women had normal cervical results.

According to the guidelines, clinicians should stop screening in women older than 65 years if they meet certain qualifications (eg, no history of CIN 2 or higher, adenocarcinoma in situ, or cervical cancer) and have also had 3 consecutive negative cytology results or 2 consecutive negative co-test results within the previous 10 years, with the most recent test occurring within the last 5 years.

Prior to the time of a rescreening exam, there must be verification of the personal data, income, insurance information and information about current health status. Therefore, the IBCCP Health Assessment Form is to be completed at a minimum annually to
determine if any changes in health status have occurred since the previous screening. An IBCCP Eligibility Determination Form must be completed for each screening cycle.

The Program’s ability to provide rescreening services is dependent upon the funding resources available in each Lead Agency. Agencies must balance the funding available to ensure clients who need assistance, (i.e., abnormal results) will receive services through the entire fiscal year.

5.9 CLIENT EDUCATION

Contracted agencies and screening medical providers are required to provide information and education on the early detection of breast and cervical cancer. The purpose of the education component is to provide clients with information necessary to understand screening procedures and to motivate them to comply with required guidelines for screening.

The education provided should be appropriate to the client’s age, ethnicity, lifestyle, educational level and medical history. Clients are to be given the opportunity to ask questions and encouraged to verbalize an understanding of the educational information provided. Information is to be presented in a non-technical manner when appropriate.

Education must be documented in the client’s medical record (provider and funded agency). Health education literature supporting the need for screening procedures is to be given to the client.

5.10 FOLLOW-UP SERVICES FOR NORMAL RESULTS

A.) The frequency of services provided are to be determined by the breast and cervical cancer screening algorithms which are based on the appropriate standards of care and in accordance with the CDC and IBCCP policy.

B.) The Nurse Clinical Patient Navigator (Case Manager) or Patient Navigator (Case Management), Assistant under the direction of the registered nurse assigned to each client, is responsible for managing the follow-up procedures and reporting all activities in the client file.

C.) The client must be notified of her results within 30 days of the test performance and advised of the recommended time for re-screening.
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5.11 METHOD OF CLIENT NOTIFICATION FOR NORMAL RESULTS

A.) First follow-up letter or telephone call:

1.) A letter will be mailed (or a telephone call made) to the client indicating the clinical findings and the recommended follow-up.

B.) Second follow-up letter or telephone call:

1.) If no successful contact has been made with the client, then within two weeks after sending the initial letter, a second follow-up letter (or telephone call) will be sent to the client.

2.) The above must be documented in the client’s file.

C.) Third follow-up:

1.) If there is no response after sending the second letter (or phone call), a third attempt must be made within 10 days.

   a.) The third follow-up must be documented in the client’s file. Client notification must be documented in the client’s record (Screening Summary/Office Visit Form) and in Cornerstone on the PA 30 Screen under “Screening Notification Date.” Copies of the letter(s) must be maintained in the client’s file or per the agency’s protocol. Agencies who have a protocol for standardized form letters must maintain those letters for review. Refer to Section 10.7- Closing Out Client Screening Cycles in Cornerstone to assure proper documentation has occurred in Cornerstone.

5.12 TRACKING

A.) Clients who have been previously enrolled and screened through the IBCCP will be tracked in order to facilitate re-screening services (Cornerstone Report HSPR0786).

B.) The staff at each contracted agency is responsible for identifying, on a monthly basis, which clients are due for clinical exams.
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C.) Based upon funding availability, agencies whose clinical funding will accommodate re-screening are to mail personalized reminder notices or contact the clients by phone. If reminder notices are mailed, the clients will be encouraged to contact the Clinical Patient Navigator (Case Manager) to verify eligibility and schedule appointments. If the clients are contacted by phone, the Clinical Patient Navigator (Case Manager) must verify the women’s continued eligibility during this call and offer to schedule appointments for them.

D.) The IBCCP staff will make a second contact attempt, within 2 weeks by telephone to the clients who have not responded to the first re-screening reminder. If no appointment has been made the client is to be encouraged to do so. The Clinical Patient Navigator (Case Manager), or designee, can offer to schedule the appointment for the client if the client agrees to such. If not already completed, verification of the women’s continued eligibility is to be made during this call.

E.) The Clinical Patient Navigator (Case Manager) must document all rescreening reminder contact attempts in the client’s file and/or in the case notes in Cornerstone.

5.13 LACK OF SPECIALTY SERVICES ACROSS SERVICE AREAS

The mission of IBCCP includes the screening of medically underserved women for breast and cervical cancers and providing appropriate referrals. Primary medical providers including general practitioners, obstetricians, gynecologists, internists and family practice physicians, as well as nurse practitioners and physician assistants deliver these services. Additionally, the Program ensures timely diagnostic follow-up, clinical patient navigation (case management) and assurance of medical treatment for women with abnormal screening tests. In some cases, specialty care is necessary to ensure a positive health outcome for the client.

In Illinois, the lack of specialty care medical providers in many parts of the state remains a serious barrier to health care. Without access to appropriate medical providers, many women may not receive timely diagnostic and medical treatment. All women enrolled in IBCCP must be assured of access to necessary services in accordance with Centers for Disease Control and Prevention, National Breast and Cervical Cancer Early Detection Program (NBCCEDP) guidelines.

Due to the lack of specialty services available in some areas of the state, it may become necessary for an IBCCP-eligible client to be referred to a Lead Agency in another area of the state, for services not available locally. These cases will be handled on a case-by-
case basis and must have prior approval from the Illinois Department of Public Health.

If a client requires services not available to her in the service area defined by the Lead Agency contract, the project coordinator of the Lead Agency where the client is enrolled must contact the IBCCP Program and Policy Supervisor to discuss options for ensuring service availability. The state IBCCP staff will recommend options to facilitate the Lead Agency in obtaining necessary services for the client in accordance with NBCCEDP guidelines. These recommendations may include referral to another Lead Agency or to a practitioner or health care facility located in another IBCCP service area. The IBCCP Program and Policy Supervisor will inform the receiving Lead Agency of the referral. All results must be entered into Cornerstone prior to the transfer as delineated in Section 5.14.

All IBCCP grant-funded agencies, including those agencies receiving funds through subcontracts with Lead Agencies, are required to provide appropriate services to eligible women enrolled in the screening Program. In the event that an agency is requested to enroll a client from another service area, the client must be treated with the respect and courtesy afforded to every IBCCP eligible woman. All services available to IBCCP clients must be made available to referred clients. The state IBCCP staff will determine, on a case-by-case basis, the need for caseload and budget adjustments in such situations.

5.14 MOVING BETWEEN SERVICE AREAS IN ILLINOIS

A.) When a client moves to a different IBCCP service area within Illinois, the Clinical Patient Navigator (Case Manager), or designee, must notify the appropriate IBCCP funded agency within the area of this move and provide a new address, if known, so that the client can be enrolled in another service area. The new address and telephone number should be documented on the client’s most recent Client Eligibility Determination Form and in the case management notes.

B.) Clients must be transferred between IBCCP Agencies within the state utilizing Cornerstone. The request for transfer must be initiated by the Nurse Clinical Patient Navigator (Case Manager) at the new location by using the request for transfer using the “Request for Client Transfer” Form in Appendix E.

C.) Cornerstone will automatically terminate the client 30 days after the last service entry after a successful End of Day (EOD) and Beginning of Day (BOD) message. The agency that is requesting the client transfer must have a successful BOD. As long as all agencies’ EOD/BOD is current, the process should only take one day. If the current agency has outstanding bills not entered into Cornerstone
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more than 30 days after the last service entry, the Clinical Patient Navigator (Case Manager) at the current agency will need to contact IBCCP State Data Manager to resolve the data entry issues.

D.) Within 5 calendar days of the transfer request being completed by the Nurse Clinical Patient Navigator (Case Manager) or designee at the agency where the client was terminated will submit copies of:

- The client’s entire Cornerstone SV06 report (Procedure History Inquiry), and;
- The two most current Breast and Cervical Cancer Data screens from the PA30, and;
- Any other pertinent abnormal data that is necessary to continue services for the client.

These are to be sent to the Clinical Patient Navigator (Case Manager) at the new agency where the client has relocated via fax or mail.

5.15 CLIENTS WHO RELOCATE OUT-OF-STATE

A.) When a client moves to another state, the Nurse Clinical Patient Navigator (Case Manager), or designee, must notify a staff member in the BCCP Program of that state. The CDC website (http://apps.nccd.cdc.gov/dcpc Programs/default.aspx?NPID=1) lists contact information for all state Breast and Cervical Programs. Document the client’s relocation on the IBCCP Eligibility Determination Form.

B.) If requested by the BCCP contact in the new state, the Nurse Clinical Patient Navigator (Case Manager) or designee will submit copies of the client’s enrollment, health history, screening and diagnostic forms to the IBCCP contact.

5.16 TERMINATING CLIENTS

Clients are to be terminated from the Program when:

A.) the woman is no longer eligible because she has Medicare Part B, Medicaid, or private insurance that pays for breast and cervical cancer screening tests;

B.) the woman no longer meets income guidelines for the federal Program (she may continue to receive services under the state funded Program);
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C.) the woman’s deductible has been met for insurance

D.) the woman no longer desires to participate/refuses;

E.) the woman is lost to follow-up after three (3) documented contact attempts; **Refer to Section 10.7- Closing Out Client Screening Cycles in Cornerstone to assure proper documentation has occurred in Cornerstone.**

F.) the woman expires;

G.) when the woman has been accepted to the Breast and Cervical Cancer Treatment Unit at the Illinois Department of Healthcare and Family Services; and

H.) IBCCP is the payor of last resort. Women who can receive screening services through Family Planning, Stand Against Cancer, and other similar programs must be terminated when the screening and diagnostic cycle is complete and no cancer has been found. They may be reactivated if the results of future screening tests are abnormal.

I.) In the event that IDPH or the Grantee substantiates that an individual receiving services under the IBCCP knowingly misrepresented that individual’s lack of insurance, IDPH reserves the right to require the Grantee to withhold further services for that individual. Subsequently, the Grantee will notify IDPH that services for that individual have been withheld. Further, IDPH reserves the right to pursue compensation for the cost of providing screening and other services from any individual that either IDPH or the Grantee substantiates knowingly misrepresented that individual’s lack of insurance.

** It should be noted that a client will be terminated at the current site once transferred to a new site (Refer to Section 5.14)

5.17 TREATMENT RESPONSIBILITIES

A.) Federal and State IBCCP funds cannot be used to reimburse for treatment services, except as provided in B) below.

B.) State funding continues to be available to pay for the treatment of CIN 2.

C.) Per the mandates of the Breast and Cervical Cancer Mortality Prevention Act of 1990, necessary follow-up and timely treatment must be afforded to all women
who participate in the Program.

D.) IBCCP contracted agencies must assure timely state-of-the-art treatment by medical providers and/or hospitals for those women who are ineligible for Medicaid enrollment or refuse Medicaid enrollment and require assistance.

1.) Payment for treatment services must come from private sources, community based sources, other governmental grants or provided pro bono by the provider. Cost-agreeable services may be negotiated on a client-by-client basis.

E.) Clients who qualify for the Medical Benefits for Treatment are to be referred as outlined in Section 8.

5.18 TRANSPORTATION

Arrangements for transportation for clients to obtain screening and/or diagnostic services are to be made at the local level. Transportation for clients is a reimbursable service using the client services and support portion of the grant funds and must be included in the annual budget. This includes bus tokens, public transportation, taxi fees, or gas cards.

5.19 WOMEN WITH DISABILITIES

AMERICANS WITH DISABILITIES ACT (ADA) OF 1990

The ADA gives civil rights protections to individuals with disabilities, similar to those provided to individuals on the basis of race, origin, age, gender, and religion.

Every organization that serves the public is legally obligated to abide by the ADA. This means that among other things, an organization must make accommodations in order to make services and products available to people with disabilities. The ADA requires that medical providers remove physical barriers if readily achievable and make reasonable modifications in policies, practices and procedures to accommodate people with disabilities.

REHABILITATION ACT OF 1973

Section 504 of the Federal Rehabilitation Act of 1973 requires that any program or service receiving federal financial assistance, either directly or indirectly be accessible to everyone. Most public services fall into this category, including health care facilities.
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BARRIERS TO CARE FOR WOMEN WITH DISABILITIES

Accessible care begins by making sure that people with disabilities can enter the medical facility or office to receive services. Accommodations need not be expensive. The simplest and least costly modifications are often the most effective. Women with disabilities experience a wide range of barriers in obtaining and receiving health services due to physical, emotional and practitioner barriers. Some examples are:

Physical Barriers:
- difficulty transferring to a standard exam table,
- difficulty with positioning on the exam table,
- difficulty standing or maintaining position for mammogram,
- lack of transportation, and
- lack of personal assistance during appointment.

Emotional Barriers:
- pre-occupied with other health issues,
- fear of being a burden,
- prior negative experience, and
- history of sexual abuse.

Practitioner Barriers:
- not acknowledging relevance of women’s health issues versus disability related health issues,
- not knowing how to provide assistance,
- fear of injury to self or client, and
- lack of knowledge about disability.

ACCESSIBILITY TO SERVICES

Adapting the breast and cervical screening procedures may be necessary during the exam or mammogram. Some examples include assisting the client with tasks such as dressing or undressing, using pillows or foam wedges for positioning and transfer assistance onto the exam table.

Improving Access:
- motorized, adjustable-height treatment and examining tables and chairs;
- mammography machines that can accommodate a woman in a seated position;
- spaces left open but dispersed in waiting areas where wheelchair users can sit out of traffic lanes but with other people;
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- a portable, amplified communication system or device with volume control at
service desks and treatment spaces for people who are hard of hearing;
- more than one accessible toilet and dressing room;
- weather protection at entrance doors; and
- power door operators at interior and exterior entrances.

COMMUNICATION

A woman with a disability is an expert regarding her body and her disability. She needs
to be given an opportunity to communicate this knowledge and how to accommodate her
functional limitations.

- Always ask the woman what accommodation she feels may be necessary. Never
assume a person with a specific disability will need a specific accommodation.
- Treat all people with respect and courtesy.
- Always speak directly to the woman receiving the exam. Often women with
disabilities are ignored or treated as though they are not capable of making their
own decisions. It is important to not focus on the attendant, interpreter or family
member.
- Use direct eye contact. Eye contact communicated a level of comfort and trust
with a client that enhances communication.

Examples of auxiliary aids to assist communication are:

- experienced Sign language interpreters,
- telecommunication devices for the deaf (TDD) or Teletype (TTY),
- health information in Braille, large print (Arial 14 point), audio tapes or computer
disks,
- written information with clear explanations.

5.20 HEALTH ISSUES FOR WOMEN PARTNERING WITH WOMEN

Providing culturally competent care to lesbians and women who partner with women
requires an awareness of health care needs related to the woman’s sexual orientation. It
is important to build the skills of medical providers and their office staff to promote
change in practice approaches through education and technical assistance. Medical
providers need knowledge of the special needs of lesbians and how they can
communicate their expertise and acceptance to their patients. In addition to the issues of
access to care, which affect all women, lesbians and other women who partner with
women may face barriers unique to homosexual identity or behavior.
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Physical Barriers:
- poverty;
- lack of insurance coverage under the partner’s policy;
- not knowing where to go for culturally sensitive care;
- concern that disclosure may result in loss of child custody, job, and other social support; and
- exclusion of partner from health care settings and decisions.

Emotional Barriers:
- fear that disclosure of sexual orientation will compromise care or risk denial of care;
- past history of sexual or physical abuse, possibly from a provider; and
- Internalized oppression or low self-esteem.

Practitioner Barriers:
- provider and staff attitudes and behaviors;
- lack of valid research about the needs of lesbians and WPW;
- inaccurate knowledge about screening needs of WPW including STD’s, HIV, and cervical cancer; and
- lack of information/awareness of care needs of lesbians and WPW;

IMPROVING ACCESS TO CARE

- Screen WPW under standard protocols for cancer screening. Treatment strategies are the same regardless of sexual orientation and must be offered without discrimination.
- Health assessments must include sexual histories inclusive of all persons without assuming heterosexual relationships.
- Treat all clients and patients with the same respect that you would wish to be shown. Do not attempt to press your personal views, show personal bias or judgment.
- Use the terms “partner” or “significant other” rather than “he” or “she” to indicate relationships.
- Ask questions if you are unsure of what “someone” means. It is better to admit that you don’t understand but are willing to learn than offer a false impression of understanding.
- Providing respectful, sensitive health care does not require that the provider must agree with someone’s behavior or beliefs.
SECTION 5 CLIENT SERVICES

- Display health education posters, magazines and other written material that reflect various family configurations.

Rather than ask about marital status ask about significant relationships or “Who do you live with?” This is especially important when asking about emergency contacts. Another important question would be, “What is that person’s relationship with you?”

5.21 HEALTH-LINE REFERRALS

HISTORY

The Women’s Health-Line was based on a Helpline from the Illinois Department of Human Services called “Help Me Grow”. The Office of Women’s Health started the toll-free Health-Line in 1999 to try to fill in the gap to assist women with their health care needs. The Health-Line’s phone number is 888-522-1282.

PURPOSE

The Health-Line’s purpose is to provide health information and referrals to women throughout Illinois. Navigating the health care system is difficult and the Health-Line assists women by connecting them to the appropriate agencies. The Illinois Breast and Cervical Cancer Program (IBCCP) is the primary referral given to the majority of the Health-Line callers. In addition, the Health-Line provides health information and materials to individuals and agencies for outreach into the community.

DUTIES

A.) Answer Women’s Health-Line and refer callers to the appropriate agencies or staff.

B.) Provide materials to callers as requested.

C.) Collect and update resources for the Health-Line database.

D.) Compile summary reports relating to the Health-Line.

E.) Provide Quality Assurance for the Health-Line to see if callers were referred appropriately.

F.) Develop and maintain procedure guidelines for the Health-Line.
**SECTION 5  CLIENT SERVICES**

**HEALTH-LINE STAFF**

There are full-time English and Spanish speaking staff available for callers. For other languages, interpreters may be available upon request.

**IBCCP REFERRALS**

The majority of referrals for the Health-Line are for the Illinois Breast and Cervical Cancer Program. Clients call the Health-Line and their contact information is entered into the Health Line database on a referral form. The Health-Line searches for the closest local IBCCP agency (according to zip code) and the referral (Appendix E) is e-mailed to the agency’s first contact. If the first contact is unavailable, the second contact is e-mailed the referral. It is important that the agency contact information is kept up-to-date so the referral is not lost. Additionally, Lead Agency staff should also notify the Health-Line for any changes in the Lead Agency contact information including permanent or temporary changes such as vacations or illness. This contact information should include: name, phone, fax and e-mail address for the first and second contact. In addition, if the IBCCP agency has a public phone number for the Health-Line to provide to clients, that information should also be included. The Lead Agency must make three documented contact attempts within two weeks of receiving the referral to begin the enrollment process.

If a Lead Agency receiving the referral determines that the client lives closer to another Lead Agency, the Quality Assurance Nurse must approve the transfer. If the request is approved, the Lead Agency staff must then notify the Health-Line staff of the assignment change via email.

**HEALTH-LINE COMPLAINTS FROM IBCCP CLIENTS**

When a caller contacts the Health-Line regarding a complaint that they were not contacted by the Lead Agency after being referred by the Health-Line or the client was contacted but no appointment was made, if the client’s referral was sent less than two weeks from date of the complaint, the client is given the agency’s phone number to contact the agency directly. If the client has not heard from the agency after two weeks from when the referral was sent, then the referral is resent via e-mail to the first contact and carbon copied to the Quality Assurance Nurse, the IBCCP Program Supervisor, the Population Health Management Division Chief, and the Health-Line supervisor. A copy
is made and given to the IBCCP Program Supervisor’s staff to log into a spread sheet to allow for proper follow-up.

**HEALTH-LINE QUALITY ASSURANCE REPORTS**

The Women’s Health-Line utilities a Quality Assurance System that monitors the effectiveness of the overall Health-Line’s referral operation, as well as the specific referral system related to the Illinois Breast and Cervical Cancer Program (IBCCP). The intent of the Quality Assurance System is to assess client satisfaction.

Each month, Health-Line staff, randomly selects 20% (approximately every 5th caller) who were referred to the IBCCP program. The Health-Line staff phones these clients and fills out the Health-Line Quality Assurance Form to determine the length of time it took to be contacted by the agency, whether they were enrolled as an IBCCP client, and the level of satisfaction they received. If the caller has not been contacted by the IBCCP agency or has not received an appointment within two weeks, the Health-Line resends the referral and follows the same procedure utilized for client complaints. The Quality Assurance Summary Report includes that Health-Line information related to the callers that responded to the Quality Assurance Form and the client’s level of satisfaction. This report is shared with the Office of Women’s Health and Family Services so that proper follow up from IBCCP program staff to the Lead Agencies can occur.

**IBCCP MATERIALS ORDERED THROUGH THE HEALTH-LINE**

The Health-Line sends out the materials for the Office of Women’s Health and Family Services. The order form can be found in Appendix E – form “u” and on the Office of Women’s Health and Family Services Website at [www.idph.state.il.us/about/womenshealth/owh.htm](http://www.idph.state.il.us/about/womenshealth/owh.htm) or at [www.cancerscreening.illinois.gov](http://www.cancerscreening.illinois.gov). Agencies should allow one-two weeks for delivery after an order has been placed.

**HEALTH-LINE IBCCP AGENCY RELATIONSHIP**

The relationship between the Health-Line and IBCCP is integral to the success of the IBCCP program. As with all relationships, communication is the key. Lead Agencies should contact the Health-Line staff if any issues arise. The goal of the IBCCP program is to provide screening services for breast and cervical cancer and the Health-Line’s goal is to link women to healthcare services. The cooperative relationship between the IBCCP program and the Health-Line are an integral part of goal attainment and serving the women of Illinois.