

Puerto Rico Breast and Cervical Cancer Early Detection Program

Data Dictionary: Form A, B and C

FORM A: Screening Breast and Cervical

Demographic Information:

Patient Last Names- patient's paternal and maternal last names

First Name- patient's first name

Birth Date- patient's date of birth. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Providers Name- name and last names of the medical doctor who is providing the clinical services

Medical Record #- this space was provided for the benefit and internal use of the provider's clinic. This variable is NOT REQUIRED by the Program.

Breast Screening Tests:

Clinical Breast Exam Results- choose one of the options for breast exam result

Date of Breast Exam- date the clinical breast exam was performed. Document in the following format (2 digits) / day (2 digits) / year (4 digits)).

Risk for Breast Cancer (NEW VARIABLE)- choose one of the following options:

High Risk for Breast Cancer- should be reported if risk was assessed and determined to be high risk (Woman with BRCA mutation, a first-degree relative who is a BRCA carrier, a lifetime risk of 20-25% or greater as defined by risk assessment models, radiation treatment to the chest between ages 10-30, or personal or family history of genetic syndromes like Li-Fraumeni syndrome.)

Not High Risk- should be reported if risk was assessed and not determined to be high risk

Not assessed- should be reported if risk was not assessed, family history was not taken, and/or genetic testing was not done or if risk is unknown.

Purpose of the Initial Mammogram- choose one of the following options:

Routine Screening- should be reported for a mammogram performed as part of a routine or

annual screening schedule and in the absence of symptoms or a recent positive clinical breast exam.

Diagnostic- should be reported for a mammogram performed as additional evaluation of a recent mammogram prior to this cycle, evaluation of current symptoms or abnormal clinical breast exam finding, or prior history of breast cancer.

Non-program mammogram, patient referred in for diagnostic evaluation- should be reported when a patient has had a mammogram performed outside of the Program, and is referred to the Program for diagnostic work-up.

No mammogram, Direct to diagnosis for short term follow up- should be reported when the patient only received a CBE or screening MRI; or when the patient does not have an initial mammogram performed and goes directly to Diagnostic Work-up.

No breast service- should be reported when no breast services are provided or reported in this record, only cervical services.

Date of Initial Mammogram- date that the initial mammogram (mammogram which started the current cycle) was performed. Document in the following format (2 digits) / day (2 digits) / year (4 digits)).

Initial Mammogram Results- choose one of the options. Please Note: Based on new BI-RADS guidance from the Fourth Edition 2003, "Probably Benign" should not be reported as the initial mammogram result unless a complete work-up was performed prior to the screening cycle either within or outside of the Program.

Follow-up- specify the follow up recommended after **all of the work up** (end of breast cycle) has been completed.

Screening MRI Results (NEW VARIABLE)- choose one of the options.

Date of Screening MRI- date that the screening MRI was performed. Document in the following format (2 digits) / day (2 digits) / year (4 digits)).

Breast- Additional procedures needed- indicate here if additional procedures are needed to complete breast cycle. If yes, please go to Form B, where you will indicate the additional procedures referred.

Cervical Screening Tests:

Has the patient had a prior Pap Test- choose one of the options. If "Yes". Please specify the date of the Previous Pap Test.

Date Previous Pap Test- patient's previous Pap test date. Document in the following format (month (2 digits) / year (4 digits))

Risk for Cervical Cancer (NEW VARIABLE)- choose one of the following options:

High Risk for Cervical Cancer- should be reported if risk was assessed and determined to be high risk, as defined as prior Diethylstilbestrol (DES) exposure and **immunocompromised patients**.

Not High Risk- should be reported if risk was assessed and not determined to be high risk.

Not Assessed/Unknown- should be reported if risk was not assessed, family history was not taken, and/or genetic testing was not done or if risk is unknown.

Purpose of Pap Test- choose one of the following options:

Routine Screening- should be reported for a Pap test performed as part of a routine screening schedule.

Patient under surveillance for a previous abnormality- should be reported for a Pap test performed on a woman under management for a cervical abnormality detected prior to this cycle.

Non-program Pap, patient referred in for diagnostic evaluation- should be reported when a patient has had a Pap test performed outside of the Program, and is referred to the Program for diagnostic work-up.

No Pap, Direct to diagnostics for short term follow up- should be reported when the patient does not have a Pap test and goes directly to HPV testing or Diagnostic Work-up.

No cervical service- should be reported when no cervical services are provided or reported in this record, only breast services.

Pap after primary HPV+ - should be reported when a Pap test is done as follow-up to a positive primary HPV test. This positive HPV test should be one of the following types: 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 66, and 68.

Unknown

Purpose of HPV Test (NEW VARIABLE)- choose one of the following options:

Co-Test/Screening- should be reported if HPV test is performed in combination with Pap test as part of cervical cancer screening.

Reflex HPV- should be reported if HPV test is performed as a follow-up test after a screening Pap test.

Test not done- test was not performed

Unknown

Date Pap Test- date Pap test was performed. Document in the following format (2 digits) / day (2 digits) / year (4 digits)).

Date HPV Test (NEW VARIABLE) -date HPV test was performed. Document in the following format (2 digits) / day (2 digits) / year (4 digits)).

Pap Test Results- choose one of the options. ASC-US = Atypical Squamous cells of undetermined

significance. "Other", refers to other Pap test result not presented among the options, please specify this results in the blank space.

HPV Results (NEW VARIABLE)- choose one of the following options:

Positive with genotyping not done/Unknown- should be reported if HPV test was positive and genotyping was not done or unknown.

Negative- should be reported if HPV test was negative.

Positive with positive genotyping- should be reported if HPV test was positive and genotyping identifies type 16 or 18.

Positive with negative genotyping- should be reported if HPV test was positive and genotyping does not identify type 16 or 18.

Unknown

Follow-up- specify the follow up recommended after **all of the work up** (end of cervical cycle) has been completed.

Diagnostic Work-up Planned for Cervical Dysplasia or Cancer- indicate here if additional procedures are needed to complete cervical cycle. If yes, please go to Form C, where you will indicate the additional procedures referred.

Comments- document here any information you consider important or relevant with respect to this patient.

FORM B: *Breast Diagnosis*

Note: This Form should be filled ONLY if additional procedures (besides screening mammogram or Screening MRI) have been ordered.

Patient Last Names- patient's paternal and maternal last names

First Name- patient's first name

Birth Date- patient's date of birth. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Provider Name- name and last names of the medical doctor who is providing the clinical services

Diagnostic Procedures- choose all the options that apply

Date of Procedure- specify the date of the procedure. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits)).

Status of Final Diagnosis- choose one of the options.

Work-up Complete- means that the diagnostic testing is complete

Work-up Pending- means that the diagnostic testing is not complete

Lost to Follow up- means that the patient could not be contacted or was not able to complete the diagnostic testing

Work-up Refused- means patient refuses to continue with the recommended diagnostic testing

Final Diagnosis- choose one of the options

Date of Final Diagnosis/Imaging- date that the final diagnosis has been established. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Status of Treatment- choose one of the options. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits)).

Follow-up- specify the follow up recommended after **all of the work up** (end of diagnostic testing's) has been completed.

Date Treatment Status- if known, establish the date treatment started. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Comments- document here any information you consider important or relevant with respect to this diagnostic testing.

FORM C: Cervical Diagnosis

Note: This Form should be filled only if additional procedures (besides Pap test or HPV test) have been ordered.

Patient Last Names- patient's paternal and maternal last names

First Name- patient's first name

Birth Date- patient's date of birth. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Provider Name- name and last names of the medical doctor who is providing the clinical services

Diagnostic Procedures- choose all the options that apply

Date of Procedure- specify the date of the procedure. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits)).

Status of Final Diagnosis- choose one of the options:

Work-up Complete- means that the diagnostic testing is complete

Work-up Pending- means that the diagnostic testing is complete

Lost to Follow up- means that the patient could not be contacted or was not able to complete the diagnostic testing

Work-up Refused- means patient refuses to continue with the recommended diagnostic testing

Final Diagnosis- choose one of the options

Date of Final Diagnosis- date that the final diagnosis has been established. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Follow-up- specify the follow up recommended after **all of the work up** (end of diagnostic testing) has been completed.

Status of Treatment- choose one of the options

Date Treatment Started- if known, establish the date treatment started. Document in the following format (month (2 digits) / day (2 digits) / year (4 digits))

Comments- document here any information you consider important or relevant with respect to this diagnostic testing.