**SEE, TEST & TREAT DATA COLLECTION GUIDANCE**

***The goal of this document is to***

* ***Outline what data should be collected in order to successfully demonstrate the value and impact of the See, Test & Treat program to potential funders, donors, and leadership***
* ***Provide guidance on HOW to collect this data in a standardized and consistent manner to programs***
* ***Provide guidance on WHEN and WHERE to collect this data***

***The document is divided up into 3 categories of questions, which are questions that the Foundation frequently gets regarding the See, Test & Treat program:***

* ***WHO does See, Test & Treat help?***
* ***HOW does the See, Test & Treat program help these populations?***
* ***WHAT is the impact of the See, Test & Treat program?***

***This document contains:***

* ***Guidance and clarification on data points***
* ***Clarification on when data will be reported (One month after program, three months after program or six months after program)***
* ***Guidance on how to collect the required data***

**WHO DID YOUR SEE, TEST & TREAT PROGRAM HELP?**This data aims to describe the population served during your program.

**DATA ELEMENT REPORT GUIDANCE SOURCE OF DATA**

|  |  |  |  |
| --- | --- | --- | --- |
| Total # screened for breast or cervical cancer at event | One month | This includes all patients who had a **screening mammogram** or were **screened for cervical cancer** using one of the following methods: 1) # screened through HPV test alone 2) # screened through Pap test alone 3) # screened through Cotesting (Pap and HPV) 4) # screened through reflex testing (Pap followed by HPV when indicated) or who had **BOTH** breast and cervical cancer screenings.  | Patient Tracking Document |
| # With no health insurance | One month | Ask ‘**What kind of health insurance do you have?** Answers: ACA/ Employer Based/ Private Health Insurance; Medicaid; Medicare; Don’t know/Not Sure; No health insurance | Pre-registration data |
| # With health insurance but report being unable to see a doctor because of cost | One month | Ask ‘**Was there a time in the past 12 months when you needed to see a doctor but could not because you could not afford it?** Answers: Yes; No; Don’t know / Not sure | Pre-registration data |
| # Who report having trouble accessing care because they don’t know where to go | One month | Ask ‘**Was there a time in the past 12 months when you needed to see a doctor but could not because you could not find one, had trouble scheduling an appointment, lack of transportation, had no child care or didn’t know where to go?** Answers: Yes; No; Don’t know / Not sure’ | Patient Survey |
| # Who do not seek preventative care regularly | One month | Ask: ‘**About how long has it been since you last visited a doctor for a routine checkup**? Choices: < 1 year; 1-2 years ago; 3-5 years ago; 5 or more years ago; Don’t know/Not sure’ | Patient Survey |
| # Who do not have a medical home | One month | Ask: ‘**Do you have one person or a group of doctors that you visit for annual wellness visits**? Answers: Yes~~;~~ No; Don’t know / Not sure’ | Patient Survey |
| # over the age of 40 Who have never had a mammogram  | One month | Ask ‘ **Have you ever had a mammogram?**’Answers: Yes; No; Don’t know/Not sure – report all that say “no” or “don’t know” | Pre-registration |
| # over the age of 21 who have never had a pap test | One month | Ask ‘ **Have you ever had a cervical cancer screening (pap/HPV) test?** Answers: Yes; No; Don’t know/Not sure- report all that say “no” or “don’t know” | Pre-registration |
| # Provided with Transportation to the Program | One month | Record # of patients who were provided with transportation to or from the program | Pre-registration |
| # Living in Medically Underserved area | One month | Ask ‘what county do you live in?’ and then report the number of those living in a county deemed as an “MUA” by the following HRSA tool: <https://data.hrsa.gov/tools/shortage-area/mua-find> | Pre-registration |
| # Provided with interpretation services during program, Languages that interpretation was needed for | One month | Record # of patients who attended the program and required an interpreter | Pre-registration |
| Describe any modifications made to make your program more culturally sensitive/appropriate (e.g., modesty gowns, LGBTQ trainings for providers, ethnic food/entertainment)  | One month | Keep track of modifications made and provide narrative on report. | Program management document |
| Race: | One month | Ask ‘Which of the following describes your race? You can select as many as apply. *Indicate #s that fall into each category*. (If you have individuals that consider themselves a race other than the ones listed, please specify the category and enter the number of individuals that consider themselves that category):**White** – (A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.)**Black or African American** –( A person having origins in any of the Black racial groups of Africa.)**American Indian or Alaska Native** – (A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.)**Asian** – (A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.)**Native Hawaiian or Other Pacific Islander** –( A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. )**Multiracial-** A person who considers themselves part of more than one group# Other Category 1# Other Category 2# Other Category 3# Declined to Answer | Pre-registration |
| Ethnicity: | One month | Ask ‘Are you of Hispanic, Latino, or Spanish origin, such as Mexican, Puerto Rican or Cuban?’#Yes# No# Declined to Answer | Pre-registration |
| Age | One month | Ask participant’s age or date of birth to get this information. | Pre-registration |

**HOW DID YOUR SEE, TEST & TREAT PROGRAM HELP THIS POPULATION ?**

 This data aims to describe what was offered at your program and what patients received at your program.

**DATA ELEMENT REPORT GUIDANCE SOURCE OF DATA**

|  |  |  |  |
| --- | --- | --- | --- |
| CERVICAL SCREENINGS |  |  |  |
| Total # screened for cervical cancer (using cytology only, HPV only, cotesting, or reflex) | One month | These are all women that were successfully screened for cervical cancer at the See, Test & Treat program | Patient Tracking Document |
| # Receiving cervical screening results same day (IN PERSON OR OVER THE PHONE FROM A MEDICAL PROFESSIONAL)  | One month | This # would include any patient that receives their PAP TEST results on the day of the program. HPV Results are not required to be provided on the day of the program. This number also includes patients who receive their results on the phone by a medical professional (voice mail does not count). | Patient Tracking Document |
| **Summary of Cervical Cytology Diagnoses and Need For Follow Up**# ASCUS with high-risk HPV# LSIL# ASC-H# HSIL  # AGC  | One-month | This includes all diagnoses made from cervical cytology at the program and follow-up recommended.  | Patient Tracking Document |
| # Identified as needing additional follow up care to cervical screenings (diagnostics or procedures such as **re-paps, colposcopies, biopsies, LEEPs, etc.**) to address abnormal test results. | One month | - this number includes all patients identified as needing follow-up after the program.  | Patient Tracking document |
| Total # Scheduled for additional follow-up care (diagnostics or procedures such as **re-paps, colposcopies, biopsies, LEEPs, etc.**) after cervical screening | One month | This number includes all patients SCHEDULED for follow up. In your 3-month report, you will report # Patients completing follow up care. | Patient Tracking document |
| BREAST SCREENINGS |  |
| # Receiving a screening mammogram | One month | These are all women that were successfully screened for breast cancer at the See, Test & Treat program | Patient Tracking document |
| # Receiving screening mammogram results within 1 week of the program (IN PERSON OR OVER THE PHONE FROM A MEDICAL PROFESSIONAL) | One month | This # would include any patient that receives their MAMMOGRAM results within one week of the program. This number only includes patients who receive their results on the phone by a medical professional (voice mail does not count). | Patient Tracking document |
| Total # Identified as needing additional follow up care for abnormal screening mammogram results. | One month | This would include diagnostic mammograms, ultrasounds, biopsies or any other follow up care that is required due to an abnormal screening mammogram result | Patient Tracking document |
| # Scheduled for additional diagnostics or procedures | One month | This number includes all patients SCHEDULED for follow up. In your 3-month report, you will report # Patients completing follow up care. | Patient Tracking document |
| OTHER |  |
| # Meeting with health insurance navigator, patient navigator or financial counselor before or during the program to explore health insurance options | One month | It is recommended that all See, Test & Treat patients should have the opportunity to meet with an individual who can help them explore their health insurance options or provide them with information on where to access preventative care in the future. After determining the flow of your program, determine how your program will keep track of the number of patients that were provided this service. | Program management document OR have navigators keep track of # patients seen |
| # Receiving health education at the program | One month | These are patients who receive health education regarding * why it is important to get regular preventative screenings
* what happens after you get your pap test or mammogram
* where to go locally for preventative screenings if you are uninsured or underinsured

This health education can be done * at the Ask a Pathologist Table
* by health educators in waiting room
* by providers during medical appointments
 | Ask designated individuals to keep track of number of women educated |
| Describe where health education was conducted, what topics were covered and who conducted the health education. | One month | Keep track of this while developing the program flow and report.  | Program management document  |
| Describe who your patients met with at the See, Test & Treat program to explore their health care options and what information was provided to them. Also describe where in the flow of your program your patients met with a health insurance navigator, patient navigator or financial counselor | One month | Keep track of this while developing the program flow and report. | Program management document |
| Describe how your program increased the visibility of pathologists and the field of pathology. | One month | Keep track of this while developing the program flow and report. | Program management document |
| Partnerships developed that will help grantee better serve their local medically underserved population | One month |  Tracked by grantee and reported at one month report |  |
| Additional Screenings, Services and Health Education Provided at Program |  |
| Partner/Organization Name, Services/Screenings, Findings/Outcomes | One month | Enter the name of all organizations who contributed to your program on the day of the event. If they provided additional screenings or social services, indicate what kind (e.g., a social service would be signing women up for health insurance or providing cancer prevention health education {list topic};additional screening could be blood pressure, Hepatitis B, STI, vision, dental, etc.). Also list organizations that contributed to children's activities and transport. For all listings, enter the # of individuals served and the outcomes of the service. | Program management document |

**WHAT IS THE IMPACT OF SEE, TEST & TREAT?**

This data reflects the impact of your See, Test & Treat program, including changes in knowledge and attitude; diagnoses made and follow-up care.

**DATA ELEMENT REPORT GUIDANCE DATA SOURCE**

|  |  |  |  |
| --- | --- | --- | --- |
| # Who Completed Survey | One Month | # Surveys completed- designate an individual in charge of ensuring patient surveys are completed after the program. | Patient surveys |
| # Who feel more comfortable going to the doctor because of See, Test & Treat | One Month | **Ask:** Did the See, Test & Treat program help you feel more comfortable about going to the doctor? **Answers:** Yes, completely, yes somewhat, no not at all | Patient surveys |
| # Who understand why they should get a pap test because of See, Test & Treat | One Month | **Ask:** Did the See, Test & Treat program help you understand why you should get a pap test regularly? **Answers:** Yes, completely; Yes, somewhat; No, not at all | Patient surveys |
| # Who understand why they should get a mammogram because of See, Test & Treat | One Month | **Ask:** Did the See, Test & Treat program help you understand why you should get a mammogram regularly? **Answers:** Yes, completely; Yes, somewhat; No, not at all | Patient surveys |
| # Who know where to get their preventative screenings because of See, Test & Treat  | One Month | **Ask:** Did the See, Test & Treat program help you understand where you can get preventative screenings in the future because of what you learned today? **Answers:** Yes, completely; Yes, somewhat; No, not at all | Patient surveys |
| # Who know what a pathologist does because of See, test & Treat | One month | **Ask:** Did attending See, Test & Treat help you understand better what a pathologist does? **Answers:** Yes, completely; Yes, somewhat; No not at all |  |
| Total # Connected to Follow Up Care for abnormal cervical cancer screening results within x months of program | Three Month, Six Month | This includes those patients that attended their scheduled follow-up care appointments, such as colposcopies, biopsies, LEEPs, etc. | Patient Tracking Document |
| Summary of Cervical Biopsy Findings#Biopsies Performed# Negative/NormalOf the Abnormal Biopsy Findings:# LSIL, CIN 1# LSIL, CIN 2# HSIL, CIN 2# HSIL, CIN 3# Cancer | Three month, Six month | This summarizes all biopsy findings and the subsequent treatment needed. In the first column, please indicate the # of patients that fall into each category that have been connected to treatment. In the 2nd column, please indicate the # of patients that fall into each category that have NOT been connected to treatment.  |  |
| Breast Screening  |
| # Patients Successfully connected to Follow Up Care (Diagnostic mammograms, ultrasounds, biopsies or FNAs) for abnormal breast cancer screening results | Three month, Six month | Please indicate all patients successfully connected to follow up care to date.  |  |
| # Diagnosed with: DCIS, LCIS, ADH, ALH, Cancer, or other lesion requiring follow up/procedures | Three Month, Six Month | In the first column, please indicate the # of patients that fall into each category that have been connected to treatment. In the 2nd column, please indicate the # of patients that fall into each category that have NOT been connected to treatment. | Patient Tracking Document |
| OTHER |  |
| #Other significant diagnoses made | Three Month, Six Month | Sexually Transmitted Diseases, etc. Anything of Note | Patient tracking document |
| Describe any successes and challenges experienced by your institution in the provision of screenings, diagnostics, treatment, or follow up care for your See, Test &amp; Treat patients. What recommendations do you have for other programs based on these successes | Three Month, Six Month |  | Project management document |

|  |  |  |  |
| --- | --- | --- | --- |
| Total # Patients Lost to Follow up | Six month | These are patients that meet the institution’s criteria of “lost to follow up  | Patient Tracking Document |
| Institution Definition of Patient “Lost to Follow Up” | Three-month, Six month | What is your institution’s standard definition of a patient that is “lost to follow up” |  |