

HRSA Patient Navigation Demonstration Program

Common Data Elements

Individual Patient Characteristics

Patient Navigator Data

Navigation Administration Data

(Quarterly Report)

FINAL

NOVA Research Company

REVISED June 25, 2009

Table of Contents

PATIENT CHARACTERISTICS (TABLE 1)	
Navigated Patient Socio-Demographic Characteristics	2
Navigated Patient Chronic Disease Information.....	5
TRACKING LOG (TABLE 2)	
Navigated Patient Tracking Log Introduction	10
Navigated Patient Tracking Log Data Elements.....	11
Navigated Patient Tracking Log Barriers	15
PATIENT NAVIGATOR CHARACTERISTICS (TABLE 3)	
Patient Navigator Socio-Demographic Characteristics	21
PATIENT VISITS (TABLE 4)	
Report of Patient Visits	25
ADMINISTRATIVE DATA (QUARTERLY REPORT)	
Quarterly Report Template	26
Site-specific data specifications are not included in this document.	

Introduction to Revised Data Elements

Several revisions have been made to the Data Elements as a result of information gained from grantee discussions and the Peer Learning Workshop.

Every attempt has been made to finalize these common data elements. In order to facilitate review, revised data elements have been highlighted in yellow.

Data elements that have been deleted from this version:

- Data Source for patient demographics, including “other data source”
- Stage of Disease (this has been merged into navigated disease variable)
- Point of Entry (this has been merged into the navigated disease variable)

Data source has been added to the Visit Table.

Socio-Demographics

	Data Element	Definition	Response Values
1.	Subject ID	<p>Unique Program-level ID code for each subject (i.e., navigated patient).</p> <p>The subject ID is a 10-digit number that consists of two concatenated ID values — a 1-digit Site ID (S), and a 9-digit unique number representing the patient (PPPPPPPP), to be assigned by the local site.</p> <p>All Subject IDs will follow the format: SPPPPPPPP (e.g., the first Subject admitted at the ABC Family Health Center associated with the CMAP site could be assigned the following Subject ID number: 3123456789; the second subject admitted at this clinic could be assigned 3123456790.)</p>	<p><<10-digit code>></p> <p>First of ten digits should be assigned as follows: 1=Palmetto 2=Texas Tech 3=CMAP 4=Lutheran 5=Memorial/South Broward 6=Northeast Valley</p> <p>9 digits assigned by site.</p>
2.	Gender	Patient's gender	1=Male 0=Female
3.	Birth Year	Calendar year of birth	<<YYYY>>
4.	Ethnicity	Patient's ethnicity	1=Hispanic or Latino 0=Non-Hispanic
5.	Race	Patient's race	1=White 2=Black/African American 3=Asian 4=Native Hawaiian/Pacific Islander 5=American Indian/Alaska Native

	Data Element	Definition	Response Values
6.	Primary Language	Primary or preferred language spoken at home	1=English 2=Spanish 3=Haitian Creole 4=Chinese 5=Vietnamese 6=Japanese 7=German 8=Italian 9=Russian 10=French 11=Other
7.	Primary Language-Other	Patient's primary language if OTHER in previous question	<<text>>
8.	Education	Patient's highest educational attainment	1=8th grade or less 2=Some high school 3=High school diploma (including equivalency) 4=Some college/vocational after high school 5=Associate degree 6=College graduate 7=Graduate or professional degree
9.	Household Size	Number of persons in household, including self	<<number>>
10.	Household Income	Household Income	1=Less than \$10,000 2=\$10,000 to \$19,999 3=\$20,000 to 29,999 4=\$30,000 to \$39,999 5=\$40,000 to \$49,999 6=\$50,000 or more
11.	ZIP Code	First 3 digits of ZIP code	<<ZIP code>>

	Data Element	Definition	Response Values
12.	Health Care Coverage/ Funding	Does patient have any type of health care coverage or funding for visits? Other government-sponsored health plans include military health, Tri-care, Indian Health Service, state-sponsored health plan, VA. Single Service Plan is a plan that covers only 1 problem or a series of visits (e.g., cancer screening/dental/care related to accident/vision/mental health/AIDS)	[Choose ALL that apply] No insurance Medicare Medicaid Private Insurance Other government-sponsored plan Single Service Plan Other
13.	OTHER Care Coverage Status	OTHER health coverage/funding specified in previous question	<<text>>
14.	Pharmacy Assistance	Does this patient receive pharmacy assistance (prior to navigation start)?	1= Yes 0= No
15.	Hospital Utilization	Did the patient report a hospital stay in the last year?	0= None 1= 1 stay 2= More than 1 stay
16.	ER Utilization	Did the patient report an ER visit in the year prior to navigation enrollment?	0= No 1= 1 visit 2= More than 1 visit
17.	Established in Primary Care	Does the patient have an established primary care provider? An established primary care provider is a "medical home" for a patient, ideally providing continuity of health care. This will include family physicians, pediatricians, and internists. A patient is considered established in primary care if the patient has made more than one visit to the provider within the past year.	1=Yes 0=No

Chronic Disease Information

	Data Element	Definition	Response Values
18.	Navigated Chronic Disease(s)	<p>Chronic disease(s) that are the focus of patient navigation. Indicate the stage of the navigated disease(s) that the patient is presenting with.</p> <p>Other diseases may be present; however, the disease(s) specified here is/are the disease(s) that are a central focus of the navigation program.</p>	<p>[Choose ALL that apply]</p> <p>Diabetes Diabetes Gestational diabetes At risk/family history of diabetes</p> <p>Hypertension Positive Screen for hypertension Diagnosed hypertension</p> <p>Congestive Heart Failure (CHF) Diagnosed CHF</p> <p>Cardiovascular Disease (CVD) At risk/family history CVD Diagnosed cardiovascular disease</p> <p>Asthma Diagnosed Asthma</p> <p>Obesity Adult Obesity Child/Adolescent Overweight/Obesity</p> <p>Depression Positive Screen for Depression</p> <p>Breast Cancer Average risk, missed mammogram appointment Abnormal finding related to breast cancer Stage I breast cancer Stage II breast cancer Stage III breast cancer Stage IV breast cancer</p>

	Data Element	Definition	Response Values
	Navigated Chronic Disease(s) (continued)		Cervical Cancer Average risk, missed pap appointment Abnormal finding related to cervical cancer Stage I cervical cancer Stage II cervical cancer Stage III cervical cancer Stage IV cervical cancer Colorectal Cancer Missed FOBT card return Abnormal finding related to colorectal cancer Stage I colorectal cancer Stage II colorectal cancer Stage III colorectal cancer Stage IV colorectal cancer Other
19.	Other Navigated Disease	Identify the other navigated disease(s), if other navigated disease specified in previous question	<<text>>

	Data Element	Definition	Response Values
20.	Comorbid Conditions	<p>Chronic comorbid conditions that could complicate patient navigation.</p> <p>A full review of medical records is not necessary; please check those conditions known by the navigator to increase the complexity of navigation.</p>	<p>[Choose ALL that apply]</p> <p>Myocardial Infarction Congestive Heart Failure Hypertension Peripheral Vascular Disease Cerebral Vascular Accident Chronic Obstructive Pulmonary Disease Asthma Cumulative Trauma Disorders Ulcer Liver Disease Diabetes Mellitus Diabetes Mellitus with complications Hemiplegia or Paraplegia Renal disease HIV/AIDS Any tumor Leukemia Diagnosed depression Dementia Other diagnosed mental illness Chronic Pain Pregnancy Sickle cell disease Other</p>
21.	Comorbid Condition—Other	Patient's comorbid condition if OTHER specified in previous question	< <text> >

	Data Element	Definition	Response Values
22.	Date Associated with Non-Cancer Primary Chronic Illness	<p>This is the date associated with the primary NON-CANCER chronic condition that is the target of navigation.</p> <p>This should be the date that identifies the patient for navigation, and should precede the start of navigation.</p> <p>If a patient is being navigated for more than one chronic disease, pick the primary disease being navigated.</p> <p>For patients that have a diagnosed condition, this should be the date of diagnosis. If the exact date is unknown, please use the information available; estimates are OK.</p> <p>For patients navigated after an abnormal screen, this is the date of their screen.</p> <p>For patients navigated to screening, this is the date of the missed screening appointment or the date that they became identified as at-risk.</p> <p>INFORMATION ABOUT NAVIGATION FOR CANCER SHOULD BE RECORDED IN FOLLOWING ELEMENTS INSTEAD.</p>	<p>< <MM/DD/YYYY> ></p> <p>OR 01/01/9996 if cancer is the only navigated disease</p>
23.	Type of Date Associated with Non-Cancer Primary Navigated Chronic Illness	<p>This variable describes the date entered in the previous data element. It is related ONLY to non-cancer chronic illnesses.</p> <p>The element provides information about the chronic disease associated with the date, as well as where in the care continuum the date occurs.</p> <p>Notably, multiple chronic diseases are being navigated for a single patient, so the date must be the one that is relevant to the primary chronic illness navigation target.</p>	<p>1=Date diabetes diagnosed 2=Date gestational diabetes diagnosed 3=Date identified at risk for diabetes 4=Date of positive hypertension screen 5=Date hypertension diagnosed 6=Date congestive heart failure diagnosed 7=Date cardiovascular disease (CVD) diagnosed 8=Date identified at risk/family history CVD 9=Date asthma diagnosed 10=Date adult obesity diagnosed 11=Date child/Adolescent Overweight/Obesity diagnosed 12=Date positive Screen for Depression 13=NO CHRONIC DISEASE DATE; only cancer is navigated 14=Other date type</p>

	Data Element	Definition	Response Values
24.	Other Date Type Associated with Non-Cancer Primary Navigated Chronic Illness	The variable contains text describing the non-cancer chronic illness date, specifying the "other date type" indicated in the date element above.	< <text> >
25.	Date Associated with Navigated Cancer	This should be the date that identifies the patient for navigation of cancer, and should precede the start of navigation. The date may be associated with a broken screening appointment, an abnormal screening finding, or diagnosis, depending on what point the patient enters the continuum of care. THE DATE RELEVANT TO DISEASES OTHER THAN CANCER SHOULD BE ENTERED IN THE PRECEDING DATA ELEMENT.	< <MM/DD/YYYY> > OR 01/01/9996 if a non-cancer disease is the only disease navigated (so there is no cancer date).
26.	Type of Date Associated with Primary Navigated Cancer	This element describes the date entered in the previous data element related to the cancer date. The element provides information about where in the care continuum the date occurs.	1=Date of broken screening appointment or FOBT card due date 2=Date of abnormal finding related to cancer 3=Date of cancer diagnosis 4=No cancer navigated (other chronic diseases navigated) 5=Other date
27.	Other Date Type Associated With Primary Navigated Cancer Date	This is a description of the "other" type of date associated with navigated cancer, specified in the previous data element.	< <text> >
28.	PNDP Enrollment Date	Month, date, and year that patient was enrolled into PNDP This is the (a) date of referral to PN, or (b) date that PN found out that a patient was eligible.	< <mm/dd/yyyy> >
29.	2 nd PNDP Enrollment Date If Applicable	If a patient is enrolled a second time, this is the date and year that a patient was re-enrolled in the navigation program. This date should be filled out only for patients that completed navigation and re-entered for a different condition or a re-occurrence of a condition	< <mm/dd/yyyy> >

	Data Element	Definition	Response Values
30.	Disease(s) Navigated for Second Enrollment Date	Description of disease(s) involved in second enrollment	<<text>>
31.	Response to Outreach	Did the patient enter the program as a result of an outreach activity undertaken by the program?	1= Yes 0= No
32.	Patient Navigation Program Status	Is navigation complete, or will patient continue to be tracked within navigation program?	1=Navigation in progress 2=Patient refused navigation [End data collection] 3=Patient cannot be reached/Lost to navigation [End data collection] 4=Navigation complete [End data collection] 5=Patient ineligible (no longer receiving care at organization) [End data collection]
33.	Reason Navigation is Complete	Specify the type of resolution if "4" selected above.	1=Screening complete; negative finding 2=Followup test complete; negative finding 3=Completed treatment 4=Achieved other target, specify 6=Not applicable (navigation is not complete)
34.	Other Target	Specify "other" target if "4" selected above	<<text>>
35.	Date of Disenrollment	The date that a decision is made not to follow a patient as part of the navigation program.	<<MM/DD/YYYY>>

PNDP Data Elements – Navigated Patient Tracking Log

Navigated Patient Tracking Log Collecting Patient Barriers and Navigator Activities/Outcomes

Purpose

The purpose of the Navigated Patient Tracking Log is to collect data on all Patient Navigator Activities related to an **individual patient**, including interactions between navigators and:

- (1) patients,
- (2) health care providers,
- (3) community service providers, and
- (4) other service providers.

In addition to information about the type of interaction, the log will collect information on barriers addressed during the interaction and health care accessed by the patient.

Data on site outreach to groups of people prior to navigation (which involves the assessment of barriers and navigator actions to address those barriers) will be collected through the Quarterly Report.

Description

Every time a navigator has contact with another person, be it a patient, health care provider, community-based organization, or social service provider, the patient navigator will complete a navigation tracking log record.

Each log entry or record will include:

Subject ID, Navigator ID, and Date

Characteristics of Communication (type, persons involved, reason)

Activity Type

Barriers Addressed

Referrals Facilitated

Navigators will also record the circumstances under which a patient is released from the navigation program.

PNDP Data Elements – Navigated Patient Tracking Log

Data Elements, Definitions, and Response Values

	Data Element	Definition	Response Values
36.	Subject ID	<p>Unique Program-level ID code for each subject (i.e., navigated patient).</p> <p>This is the same variable described in patient characteristics, page 3. The first of the ten digits corresponds to the site, while the remaining 9 digits are assigned by the site.</p>	<p><<10-digit code>></p> <p>First of ten digits should be assigned as follows: 1=Palmetto 2=Texas Tech 3=CMAP 4=Lutheran 5=Memorial/South Broward 6=Northeast Valley</p> <p>Next 9 digits assigned by site.</p>
37.	PN ID	<p>Unique ID code for each Patient Navigator. This is the same identifier described on page 24.</p> <p>The Patient Navigator ID is a 4-digit number that consists of two concatenated ID values including the 1-digit Site ID (S) and a 4-digit number representing the navigator (NNNN).</p> <p>All IDs will follow the format: SNNNN</p> <p>[E.G., The first navigator at the Lutheran site could be assigned the following ID: 41234]</p> <p>The second navigator at the Lutheran site could be assigned the following ID: 41235</p> <p>NOTE: The PN ID cannot be reassigned if a navigator leaves the PNDP program.</p>	<p><<5-digit code>></p>
38.	Navigation Activity Date	<p>Calendar date when PN communicated with a patient or patient's family/caregiver or took action on behalf of the navigated patient.</p>	<p><<MM/DD/YYYY>></p>
39.	Start Time of Activity	<p>Time and date can be used to determine a unique communication activity.</p>	<p><<NN:NN>></p>

PNDP Data Elements – Navigated Patient Tracking Log

	Data Element	Definition	Response Values
40.	Communication Type	<p>ONLY ONE TYPE OF COMMUNICATION SHOULD BE CHECKED FOR EACH ACTIVITY</p> <p>Indicate the type of communication.</p> <p>“Communication” includes face-to-face meetings, telephone calls, and/or written communication (email, letter, forms, & other mail) between the patient, patient’s family, medical or non-medical staff, or community agency/organization staff AND the navigator. Communication may be initiated by the navigator or by other persons.</p> <p>“Accompaniment” means the navigator accompanied patient to appointment. Others such as family members, physicians, nurses, & other providers <u>may or may not</u> be present during the encounters with navigated patients.</p>	<p>CHOOSE ONLY ONE</p> <p>1= Telephone conversation 2= Home meeting 3= Face-to-face meeting at clinic 4= Written communication/email 5= Accompaniment to health care visit 6= Accompaniment to social services site 7= Accompaniment to community organization 8= Other 9= No contact on call for patient 10=Message left on call for patient 11=Message left on call for other</p>
41.	Other Type of Communication	Specify “other” type of communication	<<text>>
42.	Person(s) Involved in Communication	<p>Indicate who the communication was with.</p> <p>“Social Network” includes family, friends, neighbors, church, as appropriate.</p> <p>“Health care provider” includes physicians, nurses, physical therapists, dentists, pharmacists, social workers, and mental health providers providing services within the health care setting.</p> <p>“Healthcare staff” includes receptionists, hospital/clinic billing personnel, other patient navigators, and referral staff in health care facilities (e.g., hospitals, clinics).</p> <p>“Community resource staff” includes staff from ACS, state agencies, housing agencies, transportation agencies, social workers in outside organizations, food bank, utility companies, legal aid, etc.</p>	<p>1= Patient 2= Social network (family, friends, etc.) 3= Healthcare provider 4= Healthcare staff 5= Community resource staff 6= Other</p>

PNDP Data Elements – Navigated Patient Tracking Log

	Data Element	Definition	Response Values
43.	Other Type of Person Involved	Specify "other" type of person if "6" selected above.	<<text>>
44.	Reason For Communication	<p>What is the reason for the communication?</p> <p>"Reminder call" indicates a telephone call to prompt a patient to go to an appointment.</p> <p>"Patient Education" indicates that PN provided patient education, helped patient understand literature, or assisted in the education of the patient by another service provider OR worked with patient to identify barriers to treatment or screening.</p> <p>"Schedule Health Care Appointment" indicates that PN helped patient schedule appointment for diagnostic, follow-up, or specialty health care.</p> <p>"Schedule PN Appointment" indicates that PN is working with the patient or other person to schedule a meeting with the navigator.</p> <p>"Schedule Other Appointment" indicates that PN helped patient schedule appointment with someone other than a health care provider. Examples are community agencies (e.g., social services office) and social network (e.g., patient's family members)</p> <p>"Arrange for Medical Records" indicates that PN ensured that medical records were available when patient was referred to specialist or community agency.</p> <p>"Arrange for transportation" means navigator arranged service for patient including transportation, childcare, medical interpreter, etc.</p> <p>"Follow Up After Missed Appointment" occurs after the patient misses a health care or other type of appointment.</p> <p>"Follow Up to Provide Info on Test/Finding" means that contact is initiated for the purpose of discussing the results of a screening or diagnostic test.</p> <p>"Routine/scheduled Follow Up" means navigator is checking on a patient, either in predetermined intervals, after an appointment, during a management phase, or at another time. Note that follow up activities can be used to check on the status of a patient with any person.</p>	<p>CHOOSE ALL THAT APPLY</p> <p>Reminder call</p> <p>Patient education/Identify patient barriers</p> <p>Schedule health care appointment</p> <p>Schedule PN appointment</p> <p>Schedule other appointment type</p> <p>Arrange for medical records</p> <p>Arrange for transportation</p> <p>Follow up after cancelled appointment</p> <p>Follow up after missed appointment</p> <p>Follow up to provide info on test/finding</p> <p>Routine/scheduled follow up</p> <p>Other reason</p>

PNDP Data Elements – Navigated Patient Tracking Log

	Data Element	Definition	Response Values
45.	Other Reason for Communication	Specify "other" reason for communication.	<<text>>
46.	Patient Navigator Activities	<p>"Coordinate Health Care Services" indicates that PN is assisting patient with services and provider referrals for patient seeking diagnosis assistance, or treatment.</p> <p>"Facilitate Involvement of Community Organizations" indicates that the PN is assisting patient with gaining access to better care by coordinating efforts with other groups.</p> <p>"Notify and Coordinate Clinical Trials" indicates that PN is facilitating the enrollment of eligible patients in trials.</p> <p>"Assist Patient to Overcome Barriers" indicates that PN is anticipating, identifying, and helping patient overcome barriers to ensure prompt diagnosis and treatment.</p> <p>"Coordinate Health Care Coverage" indicates that PN is coordinating with health insurance ombudsman programs to provide patient with information on health care insurance, coverage, savings programs, and/or other publicly funded programs.</p> <p>"Assist in Seeking Preventative Care" indicates that the patient has not been diagnosed with a chronic disease, and the PN is assisting patients seeking prevention or screening care in order to reduce the patient's risk of developing a chronic disease.</p> <p>"Proactive Navigation" indicated that the navigator is ensuring that there are no new barriers and that the patient is experiencing continuity of care.</p>	<p>CHOOSE AT LEAST ONE</p> <p>Coordinate health care services/referrals (screening and/or treatment)</p> <p>Facilitate involvement of community organizations</p> <p>Notify and coordinate clinical trials</p> <p>Assist patient to identify/overcome barriers</p> <p>Coordinate health care coverage</p> <p>Assist in seeking preventative care</p> <p>Proactive navigation</p>

PNDP Data Elements – Navigated Patient Tracking Log

	Data Element	Definition	Response Values
47.	Barriers	<p>What barriers were addressed in this activity?</p> <p>NOTE: A single activity may address multiple barriers.</p> <p>Example: Patient is being navigated for abnormal mammogram and does not have transportation to clinic for diagnostic mammogram and biopsy. The barrier would be “1=transportation.”</p> <p>A detailed list and description of the navigation barriers follows this section.</p>	<p>CHOOSE ALL THAT APPLY</p> <p>Transportation</p> <p>No established primary care provider</p> <p>Location of health care</p> <p>Out of town/country</p> <p>Patient disability</p> <p>System problem with scheduling care</p> <p>Lack of access to a specialist</p> <p>Fear</p> <p>Language/interpreter</p> <p>Health literacy/lack of information</p> <p>Communication concerns with medical personnel</p> <p>Medical/mental health comorbidity</p> <p>Insurance/high co-pay</p> <p>Financial problems</p> <p>Employment issues</p> <p>Cultural/personal beliefs and perceptions</p> <p>Attitudes toward providers</p> <p>Housing</p> <p>Childcare/family care issues</p> <p>No specific barrier—maintain relationship</p> <p>Other</p>
48.	Other Barriers	Specify “other” type of barrier	<text>

PNDP Data Elements – Navigated Patient Tracking Log

	Data Element	Definition	Response Values
49.	Referrals Facilitated During Activity	<p>These are the services to which the patient has been navigated during the activity recorded on the log.</p> <p>[These are the navigation targets associated with this particular activity].</p>	<p>CHOOSE ALL THAT APPLY</p> <p>Screening Diagnostic service after screen Primary care Specialist Pharmacy assistance program Health care coverage program Social services Community resource staff (Specify type: _____) Clinical trial Health education/disease management program Other</p>
50.	Type of Community Organization	Specify type of community organization if "Community Resource Staff" selected above.	<text>
51.	Other referral assisted (Navigation Target)	Specify other target if "11" selected above.	<text>

PNDP Data Elements – Navigated Patient Tracking Log

Patient Barriers – Definitions and Examples of Above Navigator Tracking Log Barriers

Barrier	Definition	Examples
1. Transportation	Difficulty getting from home to where they obtain their health care.	<ol style="list-style-type: none"> 1. No public transportation 2. Trouble finding someone with a car who can drive them 3. Can't afford gas
2. No established primary care	Patient does not have a primary care provider or other type of medical home	<ol style="list-style-type: none"> 1. Patient reports "I don't have a doctor" 2. Patient uses Emergency Department for care
3. Location of Health Care Provider	Distance from health care facility a barrier even if you have transportation	<ol style="list-style-type: none"> 1. Care too far to walk 2. Geographic barrier (e.g. have to use a freeway)
4. Out of town/country	Patient known to be out of area during their care	<ol style="list-style-type: none"> 1. Incarcerated 2. Went home to Mexico to care for family
5. Patient disability	Disability that makes getting health care difficult	<ol style="list-style-type: none"> 1. Visual or hearing problems 2. Amputation 3. Wheelchair or walker
6. System problems with scheduling care	Care provided to patient is not convenient/ efficient to patient's needs	<ol style="list-style-type: none"> 1. Put on hold too long to make appointment 2. Had to wait too long and had to leave before appointment 3. Office hours not convenient 4. Appointment too far into the future
7. Lack of Access to a Specialist	Patient cannot schedule an appointment with a specialist	<ol style="list-style-type: none"> 1. There are not enough specialists accepting new patients 2. There are no specialists near where the patient lives
8. Fear	Fear about any aspect of medical care or their health (Note: PN may explore this, but the patient must identify this as a barrier)	<ol style="list-style-type: none"> 1. Patient states they are fearful about dying 2. Patient states they are scared about getting the test done, that test will hurt 3. Does not include only looks fearful

PNDP Data Elements – Navigated Patient Tracking Log

Barrier	Definition	Examples
9. Language/Interpreter	Health care personnel and patient do not share a common language for communication	
10. Health Literacy/Lack of Information	Difficulty understanding communication from the health care setting	<ol style="list-style-type: none"> 1. Discussion reveals patient does not understand how insulin will help her 2. Patient misunderstood need for test follow up
11. Communication concerns with medical personnel	Barriers to understanding the information given to them by medical personnel	<ol style="list-style-type: none"> 1. Didn't understand instructions by the receptionist about next appointment 2. Didn't understand physician's instruction about what the tests were about
12. Medical and mental health comorbidity (health problem that co-exists with the screening abnormality)	Medical health problems, or mental health problems (not assessed by the navigator) that make getting health care difficult	<ol style="list-style-type: none"> 1. Have bad arthritis 2. Bad diabetes or heart failure 3. Patient tells you they are severely depressed 4. Patient known to have drug abuse problems 5. Patient known to have alcoholism
13. Insurance, uninsured, underinsured, high co-pays	Paying for all aspects of health care a problem	<ol style="list-style-type: none"> 1. Medication not covered even though they have insurance 2. No insurance to pay for mammogram or ultrasound
14. Financial problems	Dealing with financial problems is interfering with receiving health care	<ol style="list-style-type: none"> 1. Not being able to pay heat, food bills, making it hard to arrange health care
15. Employment Issues	Work demands make getting health care difficult	<ol style="list-style-type: none"> 1. No sick time – therefore loses pays 2. Worried will lose job

PNDP Data Elements – Navigated Patient Tracking Log

Barrier	Definition	Examples
16. Cultural/personal beliefs and attitudes	Personal or cultural beliefs that affect patients' seeking or receiving health care as well as the way that they self-manage chronic health conditions	<ol style="list-style-type: none"> 1. Modesty 2. Cultural norms for health proscribe seeking care except in the presence of acute distress 3. Belief a test or radiation treatment is harmful 4. Puts trust in higher power as reason for not completing recommended care 5. Cultural standards for healthy weight or healthy eating conflict with medical and dietary recommendations 6. Cultural beliefs related to pride, privacy, and social status inhibit frank discussions with health care providers
17. Attitudes towards providers	Perceptions and beliefs about the health care providers that impact receiving care	<ol style="list-style-type: none"> 1. Lack of trust in health care system 2. Personal or family prior poor experience with health care 3. Community's negative beliefs about health care system
18. Housing	Worrying about where they live during their health care	<ol style="list-style-type: none"> 1. Homeless 2. Has to move to obtain care, because of their care 3. Moving frequently
19. Childcare/Family Care Issues	Not having childcare when you need for medical care	<ol style="list-style-type: none"> 1. Can't afford babysitter for your child 2. Can't find babysitter to look after grandchildren or other children you take care of 3. Can't leave elderly parent
20. No specific barrier addressed—maintain relationship	Contact with patient to preserve continuity of care. No additional barriers identified.	<ol style="list-style-type: none"> 1. Call after first chemo treatment—no barriers 2. Patient reports normal glucose levels—plans to test HbA1c next month
21. Other	Please indicate other barrier.	

PNDP Data Elements – Navigator Data

Patient Navigator Socio-Demographic Characteristics

	Data Element	Var Definition	Response Values
52.	PN ID	<p>Unique ID code for each Patient Navigator. This is the same identifier described on page 12.</p> <p>The Patient Navigator ID is a 4-digit number that consists of two concatenated ID values including the 1-digit Site ID (S) and a 4-digit number representing the navigator (NNNN).</p> <p>All IDs will follow the format: SNNNN</p> <p>[E.G., The first navigator at the Lutheran site could be assigned the following ID: 41234</p> <p>The second navigator at the Lutheran site could be assigned the following ID: 41235</p> <p>NOTE: The PN ID <u>cannot</u> be reassigned if a navigator leaves the PNDP program.</p>	<p><<5-digit code>></p> <p>First of four digits should be assigned as follows: 1=Palmetto 2=Texas Tech 3=CMAP 4=Lutheran 5=Memorial/South Broward 6=Northeast Valley</p> <p>3 digits for the unique identifier should be assigned by site.</p>
53.	Gender	Patient Navigator's gender	1=Male 0=Female
54.	Birth Year	Calendar year of birth	<<YYYY>>
55.	Ethnicity	Patient Navigator's ethnicity	0=Non-Hispanic 1=Hispanic or Latino

PNDP Data Elements – Navigator Data

	Data Element	Var Definition	Response Values
56.	Race	Patient Navigator's race	[Choose ALL that apply] White Black/African American Asian Native Hawaiian/Pacific Islander American Indian/Alaska Native
57.	Primary Language	Primary or preferred language spoken at home	1=English 2=Spanish 3=Haitian Creole 4=Chinese 5=Vietnamese 6=Japanese 7=German 8=Italian 9=Russian 10=French 11=Other
58.	Primary Language-Other	Patient Navigator's primary language if OTHER specified in previous question	<<text>>

PNDP Data Elements – Navigator Data

	Data Element	Var Definition	Response Values
59.	Additional Languages Spoken	Multiple choices	[Choose ALL that apply] English Spanish Haitian Creole Chinese Vietnamese Japanese German Italian Russian French Other/Several
60.	Additional Languages Spoken--Other	Additional Languages Spoken if OTHER/SEVERAL specified in previous questions.	<<text>>
61.	Education	Patient Navigator's highest educational attainment	1=8th grade or less 2=Some high school 3=High school diploma (including equivalency) 4=Some college/vocational after high school 5=Associate degree 6=College graduate 7=Graduate or professional degree

PNDP Data Elements – Navigator Data

	Data Element	Var Definition	Response Values
62.	Additional Education/ Training	Additional Education/Training CHW = Community Health Worker	[Choose ALL that apply] None RN LPN Medical Assistant/ Nurses Aide Social Worker Phlebotomist Radiology Technologist Mammography Technologist PN certification Community Health Worker (CHW) certification CHW training for specific condition (e.g., MCH, asthma, diabetes, etc.) Workshops/trainings Certified Medical Interpreter Traditional, Spiritual Medicine or Alternative Health Care Provider Other
63.	Additional Education/ Training-Other	Other additional education/ training relevant to navigator role specified	<<text>>
64.	ZIP Code	3-digit ZIP Code of Patient Navigator's residence	<<ZIPcode>>

PNDP Data Elements – Patient Visit Data

Patient Visits/Activities Related to Navigation Targets

All patient activities that are related to navigation activities are recorded here, including visits to health care providers, social services, community organizations, and clinical trials. Activity data may be obtained from a number of different sources, including patient self report, staff report, medical records, billing data, or other administrative databases.

	Data Element	Definition	Response Values
65.	Patient Visit ID	This is a unique identifier assigned by the site. It is used to differentiate between visits that may occur	<<7-digit code>>
66.	Subject ID	This is the same ID used throughout the demonstration, first defined as element #1 on page 2. All activities in this table will be linked to a navigated individual in the patient table.	<<10-digit code>>
67.	Date of Visit	Date of the visit or date that services were received, or date of first day of hospitalization.	<<MM/DD/YYYY>>
68.	Type of Visit	Type of visit or services received. Please make sure to include all visits that are the focus of navigation.	1=Screening Visit 2=Diagnostic Visit After Abnormal Screen (may be primary care or specialist visit) 3=Treatment in Primary Care 4=Treatment Oncologist 5=Treatment Endocrinologist 6=Treatment Ophthalmologist 7=Treatment Podiatrist 8=Treatment Mental Health 9=Health Education/Nutrition/ Disease Management 10=Pharmacy Assistance 11=Health Care Coverage Program 12=Social Services 13=Community Organizations 14=Clinical Trial Attempt 15=ER/Urgent Care Visit 16=Hospitalization 17=Other
69.	Type of Other Visit	Visit description if other visit type indicated	<<text>>

PNDP Data Elements – Patient Visit Data

70.	Length of Hospitalization	Number of days in hospital.	<<number>>
71.	Visit Data Source	Source of data for visit/activity. Note that there is no need to specify the type of data source if "other" is specified.	1=Patient Report 2=Administrative Medical Record 3=Patient and Record 4=Provider Report 5=Other

PNDP Data Elements – Program Quarterly Report

Program Quarterly Report Template

[Name of Grantee]

[Period of Performance]

During the period of performance covered by this report, please describe the program activities that took place in each of the following areas:

Program and Infrastructure Development This Quarter

What planning goals were completed this quarter?

[e.g., training manuals completed, intake forms designed, community organization training developed, internal experts scheduled to speak].

Training/Orientation/Continuing Education Session(s) This Quarter

What patient navigation training activities were completed this quarter?

[Please include continuing education and ongoing quality improvement for navigators].

Date	Length of Activity	Objective	Number PNs Attended	Number Other Program Staff Attended

Comments on Training:

Patient Navigator (PN) Staffing This Quarter

How was the PN program staffed *this quarter*?

PN Category	Number
Total number PN FTEs	
Number PNs working less than 30 hours/week on PN	
PNs providing services	
PNs hired	
PNs resigned or fired	

Comments on Staffing:

PNDP Data Elements – Program Quarterly Report

Please describe the number of patients assisted through each PN program. If there are multiple PN programs at your site, each having a different disease focus, please report the number assisted in each program. For example, please differentiate patients navigated for diabetes versus those navigated for cancer.

Number of Patients Receiving Navigation Services This Quarter	Chronic Disease Focus of Patient Navigation

Comments on Implementation:

Outreach Activities This Quarter

What types of outreach activities were conducted this quarter (e.g., presentations, health fairs, group screening, screening reminder calls, brochure/flyer distribution)? When was the outreach conducted? (Outreach activities can be distinguished from navigation in that outreach activities are more general and do NOT involve the individual assessment of a patient’s barriers with repeated patient follow up to meet a specific navigation goal).

What was the disease focus of the outreach (e.g., breast cancer, diabetes, asthma)?

If outreach was a presentation, where did it occur (e.g., church, community center, senior center, clinic)?

What is the targeted health disparity population/purpose of the outreach?

About how many persons were identified as needing services?

Date	Type	Disease Focus	Location	Targeted Health Disparity Pop	# Receiving Outreach	# Screening Positive for Services

Comments on Outreach:

PNDP Data Elements – Program Quarterly Report

Patient Navigation Recruitment/**InReach** This Quarter

Please estimate how many calls were made this quarter to recruit patients identified for navigation into the patient navigation program. For example, multiple calls may have been made to patients with an abnormal cancer screen, but these patients have not yet agreed to be navigated. The purpose of this section is to track how much effort is required to get a patient into the navigation program. This should be an estimate only.

Recruitment Calls	Recruitment Call Target

Comments on recruitment:

Lessons Learned This Quarter

What challenges were encountered, if any, and were there any lessons learned that might be useful for the future or for other sites? Please indicate what action your program took in response to the challenge. If no action taken, please specify this.

Challenge	Action Taken	Lesson Learned/ Solutions Found

Comments on Lessons Learned:

Notable Case

Please use this space to describe a case that illustrates the kind of barriers your navigators are encountering and the actions you are taking to meet patient needs.

Media Coverage

Please use this space to describe any media coverage that your program has generated.

Technical Assistance

Are there any specific areas where technical assistance is needed?