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**TITLE:** Racial Differences in Financial Impact of Prostate Cancer Treatment and Outcome

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14. ABSTRACT The North Carolina-Louisiana Prostate Cancer Project (PCaP) used rapid case ascertainment in North Carolina (NC) and Louisiana (LA) to recruit 2258 research subjects with newly diagnosed prostate cancer (CaP); African Americans (AAs). Treatments received and oncological outcomes were gathered about 4 years later from 79% of research subjects enrolled in NC and 4.4 years later from 65% of research subjects enrolled in LA. Estimations based on that initial follow-up experience and actuarial assumptions suggest that information should be collectable from 1233 living PCaP research subjects and from the surviving family members about the impact of death from CaP in 110 (about 65 AAs and 45 CAs) versus another cause in 300 (about 150 of each race) family units, respectively. The central hypothesis is that the financial impact of CaP treatment and oncologic outcome differs between AAs and CAs newly diagnosed with CaP. LA State University School of Public Health Epidemiology Data Core (EDC) will contact all PCaP research subjects who provided consent for future contact (97% allowed future contact). Treatments received and oncologic outcome will be collected using PCaP's CaP Follow-up Form and QoL will be reassessed using the same validated instruments administered by PCaP at baseline and first re-contact. Current household income, treatment costs, QoL, financial distress and caregiver QoL and stress will be ascertained using validated questionnaires. EDC will obtain the pertinent medical records and abstract them using the PCaP Follow-up Medical Records Abstraction Database. Oncologic outcome will be displayed graphically for all LA research subjects and updated for all NC research subjects using the same methodology as used to produce oncologic outcome for NC research subjects. Mortality and cause of death information is obtained via the NC State Center for Health Statistics and the LA State Tumor Registry. When PCaP research subjects have died, next-of-kin will be consented and asked to provide treatments received and physician caregivers and to complete financial, caregiver QoL and healthcare system satisfaction questionnaires modified for use by next-of-kin. Greater cost and intensity of treatment translates to greater financial burden and stress that may impact those more with less insurance, financial reserves and medical system sophistication. More non-treatment resources may be required to support men, in general, and African-American men, specifically, who suffer from CaP, but survivorship deficits require better and data-driven definition for precise intervention.					
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## **TABLE OF CONTENTS**

	<b>Page</b>
<b>1. Introduction</b>	<b>4</b>
<b>2. Keywords</b>	<b>4</b>
<b>3. Accomplishments</b>	<b>4</b>
<b>4. Impact</b>	<b>19</b>
<b>5. Changes/Problems</b>	<b>19</b>
<b>6. Products</b>	<b>21</b>
<b>7. Participants &amp; Other Collaborating Organizations</b>	<b>21</b>
<b>8. Special Reporting Requirements</b>	<b>31</b>
<b>9. Appendices</b>	<b>Attached as PDFs</b>

## 1. INTRODUCTION:

The North Carolina-Louisiana Prostate Cancer Project (PCaP) used rapid case ascertainment in North Carolina (NC) and Louisiana (LA) to recruit 2258 research subjects with newly diagnosed prostate cancer (CaP); African Americans (AAs). Treatments received and oncological outcomes were gathered about 4 years later from 79% of research subjects enrolled in NC and 4.4 years later from 65% of research subjects enrolled in LA. Estimations based on that initial follow-up experience and actuarial assumptions suggest that information should be collectable from 1233 living PCaP research subjects and from the surviving family members about the impact of death from CaP in 110 (about 65 AAs and 45 CAs) versus another cause in 300 (about 150 of each race) family units, respectively. The central hypothesis is that the financial impact of CaP treatment and oncologic outcome differs between AAs and CAs newly diagnosed with CaP. LA State University School of Public Health Epidemiology Data Core (EDC) will contact all PCaP research subjects who provided consent for future contact (97% allowed future contact). Treatments received and oncologic outcome will be collected using PCaP's CaP Follow-up Form and QoL will be reassessed using the same validated instruments administered by PCaP at baseline and first re-contact. Current household income, treatment costs, QoL, financial distress and caregiver QoL and stress will be ascertained using validated questionnaires. EDC will obtain the pertinent medical records and abstract them using the PCaP Follow-up Medical Records Abstraction Database. Oncologic outcome will be displayed graphically for all LA research subjects and updated for all NC research subjects using the same methodology as used to produce oncologic outcome for NC research subjects. Mortality and cause of death information is obtained via the NC State Center for Health Statistics and the LA State Tumor Registry. When PCaP research subjects have died, next-of-kin will be consented and asked to provide treatments received and physician caregivers and to complete financial, caregiver QoL and healthcare system satisfaction questionnaires modified for use by next-of-kin. Greater cost and intensity of treatment translates to greater financial burden and stress that may impact those more with less insurance, financial reserves and medical system sophistication. More non-treatment resources may be required to support men, in general, and African-American men, specifically, who suffer from CaP, but survivorship deficits require better and data-driven definition for precise intervention.

Table 2. Estimated PCaP Research Subject Participation about 10 Years after Enrollment

	NC	LA
Enrolled (n)	1031	1021
4 yr F/U		
- Deceased	5%	12%
- Not found	5%	7%
- Declined	1%	13%
- Participation Rate	89%	65%
10 yr F/U (estimated)		
- Deceased	10%	14%
- Not found	5%	5%
- Participation Rate	74%	46%
Research Subjects (n)	763	470

2. **KEYWORDS:** Prostate cancer; Financial distress; Financial toxicity; Caregiver; Racial disparity; Survivorship; Quality of life

## 3. ACCOMPLISHMENTS:

### Y1 Progress

There are no significant changes in the project or its direction.

### What were the major goals of the project?

There are no significant changes in the major goals of the approved research:

**Aim 1)** Locate and contact PCaP research subjects to update CaP status, CaP treatments received and comorbidities, repeat the QoL assessments performed at baseline and follow-up, and administer new surveys on financial burdens and stress and caregiver QoL and support;

**Aim 2)** Locate and contact PCaP research subjects' treating physicians to update treatments received and oncologic outcome data;

**Aim 3)** Obtain and link vital status data and cause of death in PCaP research subjects; and

**Aim 4)** Examine the role financial burden and stress have on CaP survival and QoL and whether this relationship was modified by race.

## **Y2 Progress**

We are considering a significant change in a major goal of the approved research. The updating of oncologic outcome graphs on NC Research Subjects and the construction of oncologic outcome graphs on LA research subjects will require identification of treating primary care physicians for research subjects discharged from specialty oncologic follow-up and identification of specialty physicians providing oncologic care (urologist, radiation oncologist or medical oncologist) for 1616 research subjects. Two factors suggest a need for a change in strategy. Sharing of personal health information (PHI) has become more challenging due to medico-legal concerns and more expensive because of office charges for the time necessary to access and provide PHI. The continuing evolution in clinical data availability may allow more efficient collection of these data. We have initiated a pilot project of 20 NC Research Subjects and 20 LA research subjects to determine how much oncologic outcome data can be acquired electronically. In LA, PCaP research subjects are flagged already in SEER. Dr. Peters is meeting with SEER officials to determine if we can conduct a pattern-of-care study to identify treatments received, oncologic status, and interval PSA results. In NC, Dr. Bensen will explore the use of the UNC Tumor Registry and an ongoing UNC project to access claims data for research use, which should include data from NC research subjects who have BC/BS, Medicare or Medicaid (an estimated 80-90% of NC research subjects). We will know soon if Aim 2 can be performed more efficiently and completely, which would prompt the following change:

**Aim 2)** Collect data electronically, when possible, and locate and contact PCaP research subjects' treating physicians, when necessary, to update treatments received and oncologic outcome data;

### **What was accomplished under these goals?**

**Specific Aim 1: Locate and contact PCaP research subjects to update CaP status, CaP treatments received and comorbidities, repeat the QoL assessments performed at baseline and follow-up, and administer new surveys on financial burdens and stress and caregiver QoL and support**

### **Major Task 1 Obtain follow-up from PCaP research subjects**

Subtask 1 Development: IRB approval at all sites, develop electronic and paper questionnaire forms, install and update patient and clinical medical records data tracking and collection system

## **Y1 Progress**

### **IRB approval at all sites**

A notice of probable award was received 02/07/2017. The PCaP Executive Committee discussed the potential award and what steps may be necessary to assist at its quarterly meeting 02/03/2017. Dr. Mohler traveled to LSUHSC 03/17/2017 to meet with Dr. Peters and the LSUHSC research team to begin the process of assembling and modifying the survey instruments and set a timeline for IRB approvals at UNC, LSUHSC, RPCCC and DoD. The PCaP Executive Committee reviewed progress at its quarterly meeting 07/21/2017. Dr. Mohler traveled to UNC 01/29/2018 to meet with Dr. Benson and the UNC research team to review progress toward PCaP central data base modification and data transfer agreement, and IRB approval at UNC and DoD. Dr. Mohler returned to LSUHSC 02/02/2018 to meet with Dr. Peters and the LSUHSC research team to review the final survey instruments, update the Medical Record Abstraction (MRA) form, and review the status of IRB approvals at UNC, LSUHSC, RPCCC and DoD. After collaboration with the PCaP Executive Committee and Dr. Fontham, Drs. Peters, Benson and Mohler decided to prioritize the collection of data from living PCaP research subjects and their caregivers over the caregivers for deceased PCaP research subjects.

IRB approval proved challenging for several reasons. First, LSUHSC had closed the original PCaP study, which required re-opening. Second, the DoD approval mechanism required extra time because of the complexity of the proposed research. Three institutions were involved. Two states provided research subjects who enrolled on the PCaP study 11 years ago and were re-consented to follow-up studies, one in NC and one in LA conducted at different times by different investigators. The proposed research will be conducted at LSUHSC but all data, once de-identified, will be housed at UNC. Finally, the survey instruments required that IRB applications be amended as the survey instruments were customized for the proposed research, then approved, and then submitted to DoD for final approval BEFORE we could contact the first PCaP research subject.

- **UNC** IRB protocol #17-0530, approved 01/17/18- 01/16/19.
- **RP** IRB protocol #212/BDR 083017, approved 03/10/17- 03/09/20; amended protocol approved 06/11/2018- 03/09/20.
- **LSUHSC** IRB protocol #9813, approved 08/01/17- 07/31/18; amended 03/15/2018 (re-ordering and re-wording of study instruments); amended 05/09/2018 (revision of primary care giver recruitment call script); renewed 07/03/18- 07/02/19.
- **DoD** USAMRMC, ORP, HRPO approved 07/02/18- 07/02/19.

## **Y2 Progress**

- **UNC** IRB protocol #17-0530, approved 01/17/19- 01/16/20.
- **RP** IRB protocol #212/BDR 083017, approved 06/11/2018- 03/09/20.
- **LSUHSC** IRB protocol #9813, approved 08/01/17- 07/31/18; amended 03/15/2018 (re-ordering and re-wording of study instruments); amended 05/09/2018 (revision of primary care giver recruitment call script); renewed 07/03/19- 07/02/20.
- **DoD** USAMRMC, ORP, HRPO approved 07/02/19- 07/02/20.

## **Develop electronic and paper questionnaire forms**

## **Y1 Progress**

Research subject, caregiver and medical abstraction instruments were built in REDCap, validated and tested (see Appendix items 1, 2 and 3). Pilot testing of survey instruments and REDCap database functionality has been completed. Conversion of the electronic survey instruments from REDCap to TeleForm for ease of data transfer is ongoing. Paper-based versions of all questionnaires are being prepared.

Data collection instruments: Research subjects (Appendix 1)

- Contact info
- EPIC-26
- SF 12 Version2 Health Survey
- Charlson Comorbidity Index (CCI)
- Medical Expenditure Panel Survey (MEPS)
- Comprehensive Score for Financial Toxicity (COST)
- NCCN Distress Thermometer and Problems List for Patients
- PHQ-9
- Service Satisfaction Scale of Cancer Care for PT(SSS-PT)
- Patient Satisfaction Questionnaire Short Form (PSQ-18)
- Follow-up (Health Insurance/Disease History/PA)

## Data collection instruments: Caregivers (Appendix 2)

- Contact Info
- Charlson Comorbidity Index (CCI)
- EPIC Short Form for Partners or Spouses
- Service Satisfaction Scale of Cancer Care of Partners (SSS-PA)
- NCCN Distress Thermometer and Problems List for Caregivers
- PHQ-9
- Caregiver Quality of Life-Cancer
- Montgomery-Borgatta Caregiver Burden Scale

## Medical Record Abstraction (MRA) form (Appendix 3)

- A REDCap instrument with more than 300 data collection fields was created to store the data extracted from PCaP research subject's electronic and paper health records.

## Y2 Progress

### Expansion of questionnaire methodology

The telephone-based questionnaire set was reviewed 05-13-19 and reduced in length by about 20% by eliminating redundancy brought to the investigators attention by interviewers and their research subjects' comments (Appendix 6). Skip patterns were developed to minimize un-necessary questions. Telephone interviews using the streamlined questionnaires require < 1 hour if research subjects are not "chatty." Even so, many research subjects requested a different format than telephone interviews.

A web-based questionnaire set was developed (Appendix 7). An email with a link to the questionnaires was sent to a test group of 85 research subjects, all of whom had requested a web-based instrument. A total of 64 research subjects have completed the online questionnaires, 21 online questionnaires are yet to be completed, and reminder emails are being sent and follow-up phone calls made.

A paper-based questionnaire set was developed (Appendix 8) and mailed to a test group of 125 research subjects. A total of 16 questionnaires have been completed and returned to the PCaP office in LA. Since most of the paper questionnaires were sent April-May 2019, more completed questionnaires are expected. Going forward, paper-based questionnaires will be sent out to those who don't answer the phone. This should increase the rate of questionnaire completion.

The impression of the enrollment and interview team is that research subjects prefer paper over web-site over telephone interviews for questionnaire completion.

## Y1 Progress

### Install and update patient and clinical medical records data tracking and collection system

Dr. Farnan, the PCaP Biostatistician, began work 03/01/2017 on the creation of the recruitment re-contact dataset. This required her to merge the NC-LA PCaP baseline dataset with the most current contact information for each study research subject in NC and LA from multiple datasets; the re-contact information from the 2014 re-contact effort for PCaP, the existing contact data from the 5 year HCaP-NC follow-up study, and the 2015 re-contact effort for the LA follow-up study, Q-PCaP. Vital status for all research subjects was updated from the LA SEER database (updated annually) in January 2018 and from the NC Vital Statistic database updated monthly in June 2018. This dataset was distributed to LA after DoD IRB approval was secured in July 2018.

## Subtask 2 Locate, contact and re-consent

Letters of study introduction and request to update contact information are being printed and envelopes ordered. The packets will be mailed to PCaP research subjects by 08/20/2018.

We must locate, recruit, and consent PCaP research subjects. We are anticipating to start this process 09/10/2018 (2 weeks after initial letters are sent). We will send letters in batches of 100, over time increasing to batches of 200. PCaP research subjects will be asked to provide information on treating MD(s) if different from those recorded and identify and provide contact information for their caregiver(s).

## Y2 Progress

### Enrollment time-line

07/09/18 First batch of 100 invitation letters and a form to update their contact information sent to PCaP research subjects.

10/12/18 First telephone interview conducted

10/26/18 Online survey made available for research subjects who wanted to complete the survey online

03/15/19 First batch of paper-based surveys (TeleForm) mailed

04/02/19 First completed paper-based survey received

### Enrollment progress

Research subjects' contact information/vital status databases were updated when research subject/family member reports a change of phone number/email address or vital status. Research subjects who returned the contact form to LSUHSC PCaP office with their updated contact information are the priority of the interviewers. As an alternative method, the online survey or paper-version of survey are offered to research subjects who are reluctant to complete the survey over the phone.

In a batches of 200, the PCaP follow-up letters-were mailed starting 07/09/2018 and ended on 04/30/2019. An invitation for participation and a request to update contact information were sent to all verified alive PCaP research subjects. If the mailing to a research subject returned undeliverable, contact information/vital status was searched on LexisNexis Accurint (<https://www.accurint.com/>). Acumint has found about 40 LA research subjects, 50 NC research subjects and more research subjects should be found, especially in LA where research subjects have relocated more frequently as a result of Hurricane Katrina. PCaP databases were updated when new information was found. Invitation letters were sent again to those who didn't receive it before because of a wrong or old address. PCaP research subjects received 6 phone call contact attempts for recruitment before being classified as lost to follow-up.

## Y1 Progress

### Subtask 3 Collect treatment, oncologic outcome information and identify treating MDs

Based on the progress of PCaP research subject agreement and interviews (subtask 2), we plan to contact treating MD(s) and caregivers within 4 weeks of PCaP research subject data completion.

### Subtask 4 Administer questionnaires

Additional staff are being hired.

## **Major Task 2 Obtain follow-up from caregiver/wife/partner/child(ren) of deceased PCaP research subjects**

### **Subtask 1 Locate, contact and consent**

Based on the progress of PCaP research subject agreement and interviews (subtasks 2 and 3), we plan to contact caregivers within 4 weeks of PCaP research subject data completion.

### **Subtask 2 Collect treatment, oncologic outcome information and identify treating MDs**

Based on the progress of PCaP research subject agreement and interviews (subtasks 2 and 3), we plan to contact treating MD(s) within 4 weeks of PCaP research subject data completion.

### **Subtask 3 Administer questionnaires**

Additional staff are being hired.

## **Y2 Progress**

### **Enrollment status**

The enrollment and interview team of 5 are performing well.

PCaP had a total of 1,616 living research subjects when the data collection began, based on the data received from UNC 06/12/18. Prior to that an update on vital status of PCaP LA research subjects was received 03/13/18 from Louisiana Tumor Registry (LTR). Another update on vital status from LTR was received 05/14/19.

A total of 566 research subjects have been contacted via telephone and 1000 contacts remain in progress. A total of 206 questionnaires have been completed: 41 over the phone; 95 online; and 70 paper-based.

## **Specific Aim 2: Locate and contact PCaP research subjects' treating physicians to update treatments received and oncologic outcome data**

### **Major Task 1 Obtain follow-up from treating MDs**

Subtask 1 Obtain follow-up from UNC in NC PCaP research subjects followed at UNC

Subtask 2 Obtain follow-up from NC MDs in NC PCaP research subjects not followed at UNC

Subtask 3 Obtain follow-up from SEER for LA PCaP research subjects

Subtask 4 Obtain follow-up from LA MDs on LA PCaP research subjects without follow-up in SEER

Subtask 5 Abstract data using the PCaP Follow-up Form

Subtask 7 Enter data into PCaP Medical Records Abstraction Access Database

### **Major Task 2 Construct progression graphs**

Subtask 1 Update progression graphs on NC PCaP research subjects

Subtask 2 Construct progression graphs on LA PCaP research subjects

## **Y2 Progress**

The updating of oncologic outcome graphs on NC research subjects and the construction of oncologic outcome graphs on LA research subjects will require identification of treating primary care physicians for Research Subjects discharged from specialty oncologic follow-up and identification of specialty physicians providing oncologic care (urologist, radiation oncologist or medical oncologist) for 1616 research subjects. The continuing evolution in clinical data availability may allow more efficient collection of these data. We have initiated a pilot project of 20 NC research subjects and 20 LA research subjects to determine how much oncologic outcome data can be acquired electronically. In LA, PCaP research subjects are flagged already in SEER. Dr. Peters is meeting with SEER officials to determine if we can conduct a pattern-of-care study to identify treatments received, oncologic status, and interval PSA results. In NC, Dr. Bensen will explore the use of the UNC Tumor Registry and an ongoing UNC project to access claims data for research use, which should include data from NC research subjects who have BC/BS, Medicare or Medicaid.

### **Specific Aim 3: Obtain and link vital status data and cause of death in PCaP research subjects**

#### **Major Task 1 Obtain vital statistics of NC PCaP research subjects**

##### **Subtask 1 Obtain vital statistics from NC Vital Records**

The most current data on NC PCaP research subjects is obtained monthly and is reported below through end of June 2018 (see below).

#### **Major Task 2 Obtain vital statistics of LA PCaP research subjects**

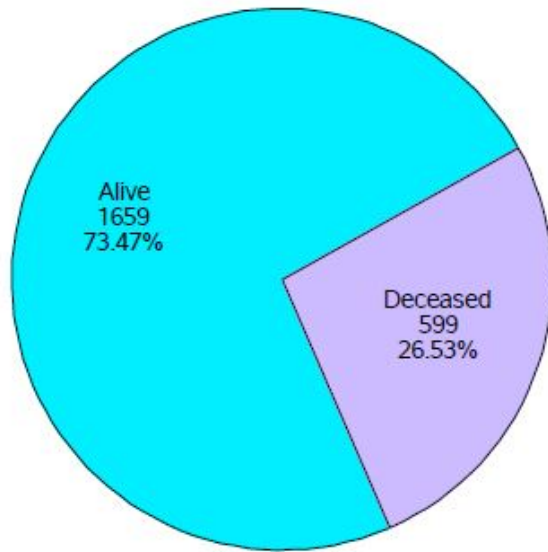
##### **Subtask 1 Obtain vital statistics from LA State Tumor Registry in Year 1**

#### **Y1 Progress**

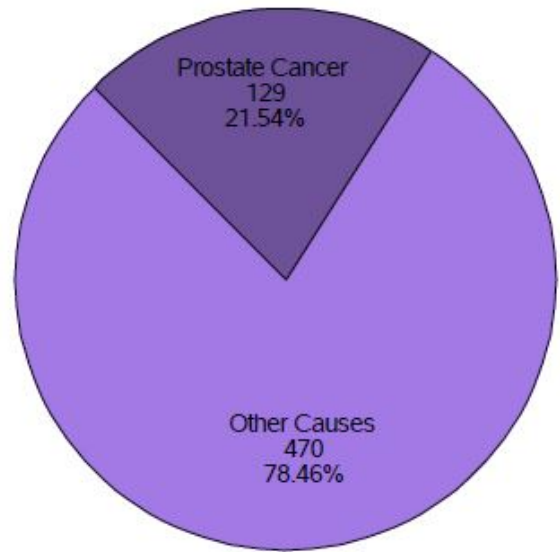
A copy of vital status of LA PCaP research subjects were sent to UNC (Laura Farnan) March 2018 (see below) that provided LA research subjects' status as of 01/01/2018 (see below). The most current data on LA PCaP research subjects will be delivered from the Louisiana Tumor Registry (LTR) in the next few days. Data received from LTR will be shared monthly going forward.

Vital Statistics for NC and LA PCaP subjects

**Vital Status**  
Total n =2258  
Number, Percent



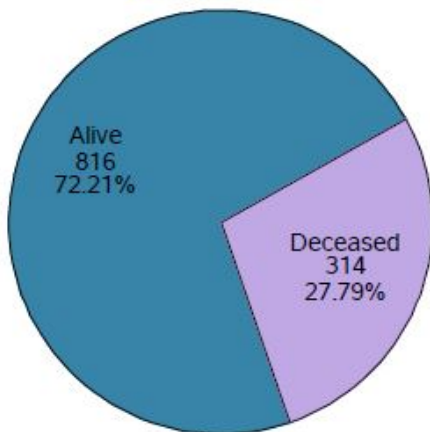
**Primary/Secondary Cause of Death**  
Deceased n =599  
Number, Percent



Vital Statistics for PCaP subjects by race

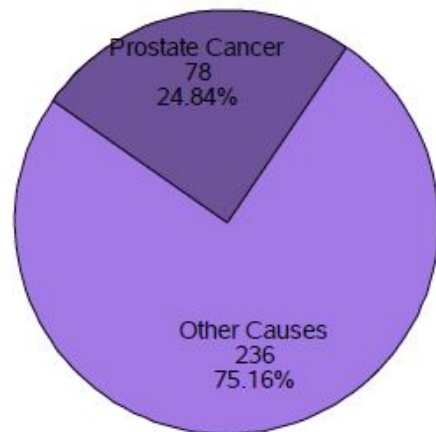
Vital Status of AA subjects

Total n =1130  
Number, Percent



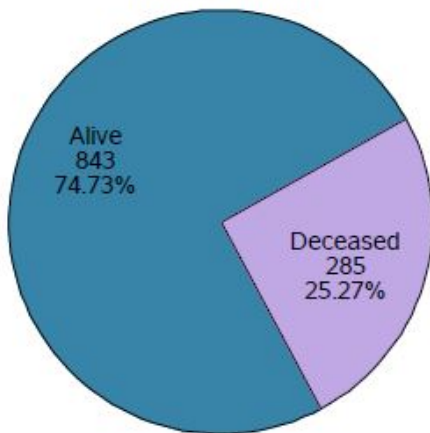
Primary/Secondary Cause of Death of AA subjects

Deceased n =314  
Number, Percent



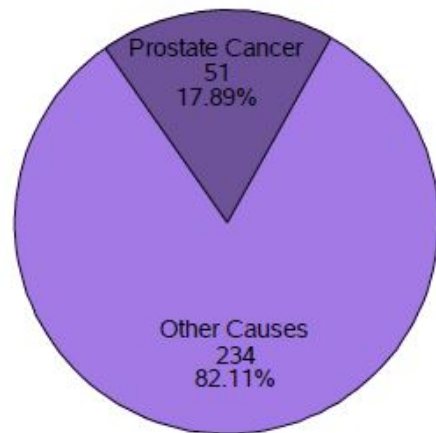
Vital Status of CA subjects

Total n =1128  
Number, Percent



Primary/Secondary Cause of Death of CA subjects

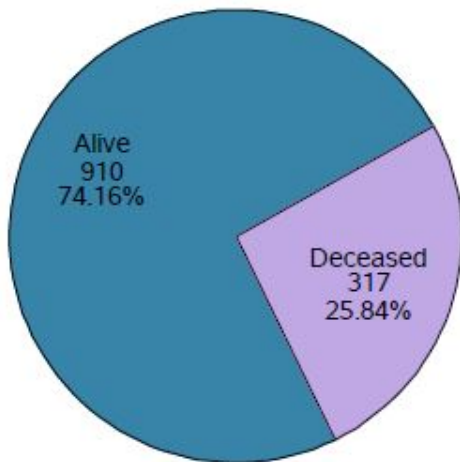
Deceased n =285  
Number, Percent



Vital Statistics for NC and LA PCaP subjects

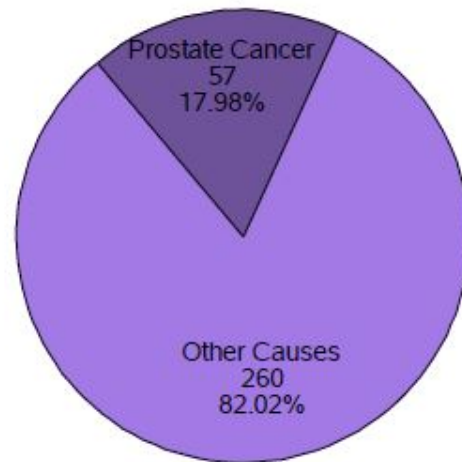
Vital Status of LA subjects

Total n =1227  
Number, Percent



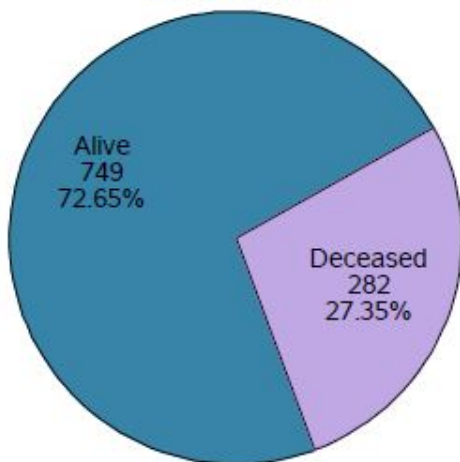
Primary/Secondary Cause of Death of LA subjects

Deceased n =317  
Number, Percent



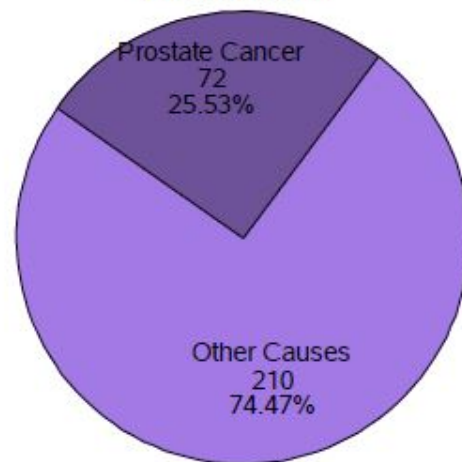
Vital Status of NC subjects

Total n =1031  
Number, Percent



Primary/Secondary Cause of Death of NC subjects

Deceased n =282  
Number, Percent

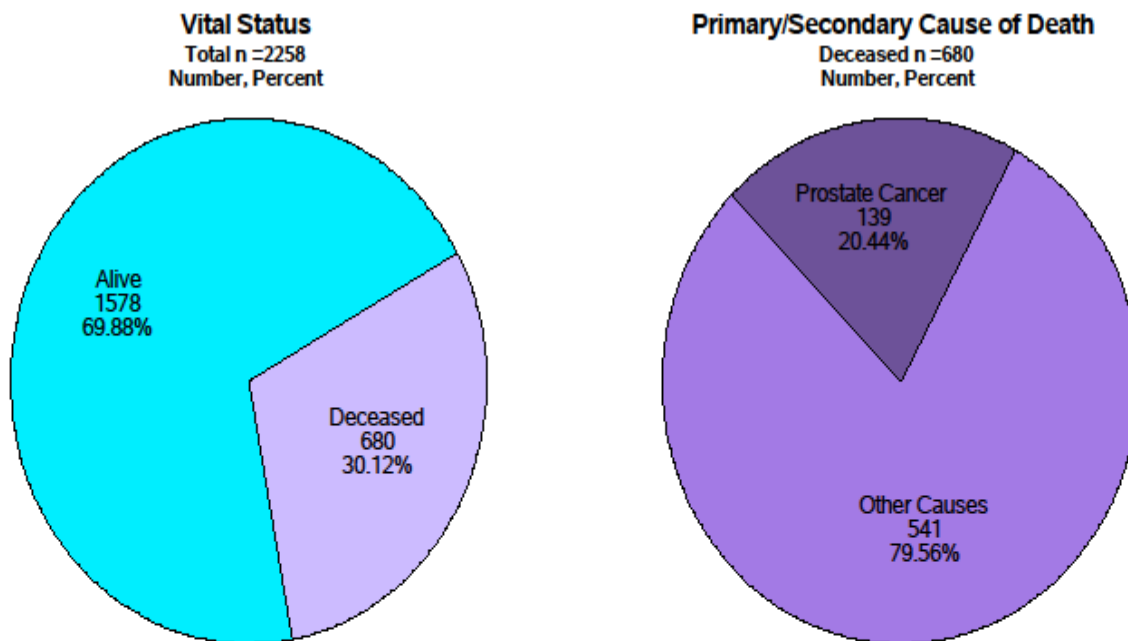


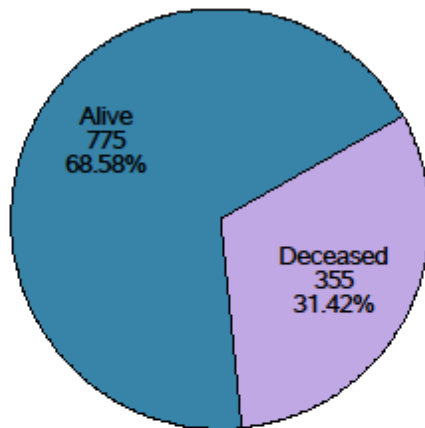
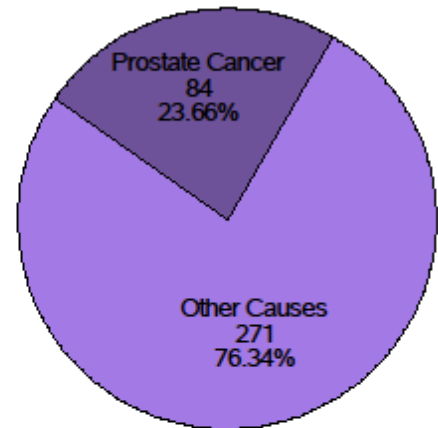
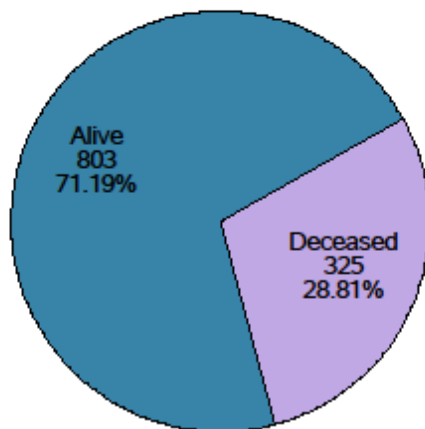
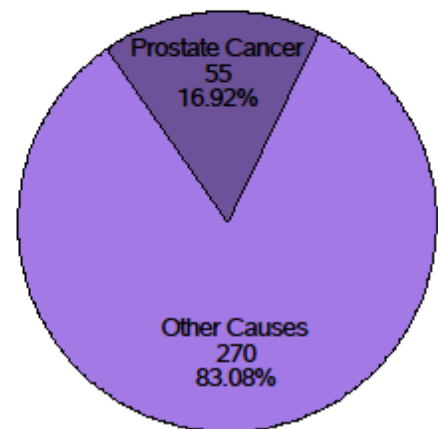
## Y2 Progress

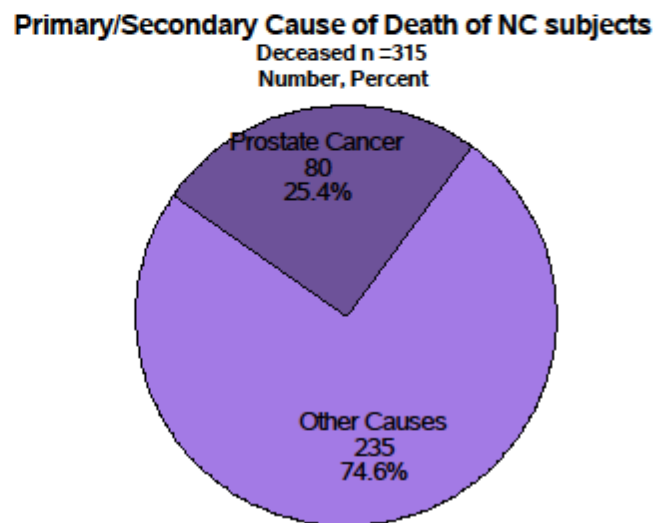
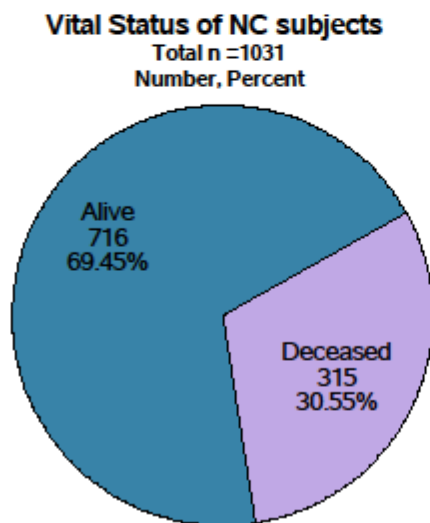
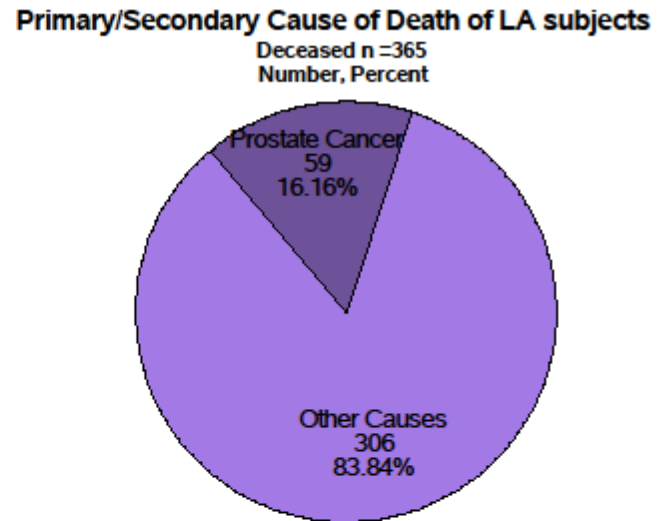
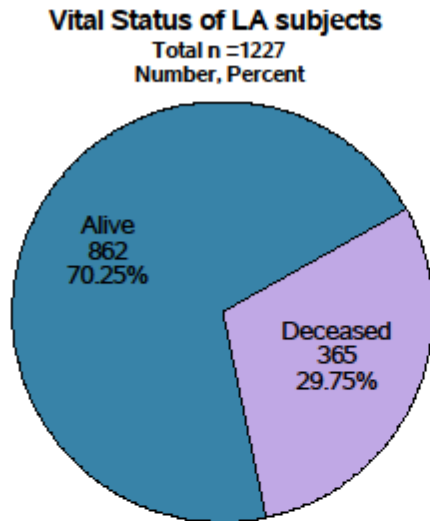
The vital statistics data reveal that we continue to have research subjects die: 81 research subjects died in the last year and 71% of all origin PCaP research subjects remain alive. The rate at which these deaths occur from prostate cancer remains relatively stable at about 21%.

Vital Statistics for NC and LA PCaP subjects

1



**Vital Status of AA subjects**Total n =1130  
Number, Percent**Primary/Secondary Cause of Death of AA subjects**Deceased n =355  
Number, Percent**Vital Status of CA subjects**Total n =1128  
Number, Percent**Primary/Secondary Cause of Death of CA subjects**Deceased n =325  
Number, Percent



### Major Task 3 Obtain vital statistics of NC and LA research subjects living outside NC and LA

Subtask 1 Obtain vital statistics form NDI of NCHS in year 1

Subtask 2 Obtain vital status of any remaining PCaP research subjects by contacting their treating physicians and family members

**Specific Aim 4: Examine the role financial burden and stress have on CaP survival and QoL and whether this relationship was modified by race**

### Y1 Progress

#### Major Task 1 Data management

Subtask 1 Maintain PCaP Data Sharing and Tracking System

PCaP diligently maintains a state-of-the-art Data Sharing Tracking System developed and maintained by the UNC Cancer Information and Population Resource (CIPHR) program. CIPHR incorporates a world class computing system with systems for data management and project tracking (ancillary studies, manuscripts), and expert staff to support and maintain these data and systems. The CIPHR secure server environment is maintained by UNC Information Technology Services and Research Computing. The CIPHR project management and tracking system is a web-based application that allows groups to manage and track studies/projects in accordance with their data governance policies. CIPHR system developers tailor each implementation of the tracking system to the particular organization. They employ the latest stable version of PHP and perform quarterly updates with emergency patching as needed. The system is housed in a Tier II Data Center with 24/7 surveillance, electronic key-card entry or sign-in with escort, redundant power sources, and climate control. The servers are behind UNC campus perimeter firewalls and have host-based firewalls exposing only ports necessary for the services in use. Servers are scanned twice weekly for vulnerabilities using QualysGuard SaaS and patched/upgraded accordingly. Over 140 PCaP investigators, nearly 20 completed ancillary studies/grants, 16 ancillary studies in progress, 40 published manuscripts and 10 manuscripts in development are archived in our Data Sharing Tracking System along with many other manuscript and grant statuses.

### Subtask 2 Create project-specific data repository

PCaP maintains a robust Central Analytic Dataset on a secure server supported and managed by the UNC Lineberger Comprehensive Cancer Center's Bioinformatics/Biostatistics Core Facility, complete with fully annotated data dictionary describing source (baseline, follow-up, or other project-specific sources), a Data and Specimen Guide, and detailed description of questionnaires available for use. User friendly, supporting documents described above can be found on the PCaP website (<https://pcap.bioinf.unc.edu/resources-protocols.php>). Details of data available are shared by Drs. Bensen (UNC PCaP/HCaP-NC PI) and Farnan (Biostatistician) with interested investigators via phone or in-person. Numerous de-identified project-specific data repositories have been deposited via project-specific folders on the secure PCaP website and this data merged with the Central PCaP Analytic Dataset by Dr. Farnan. Recently, to comply with current HIPAA and PHI standards, we established a secure Office 365 folder for transfer of datasets that contain PHI shared with PCaP established sites that have fully executed Data Use Agreements (LSUHSC, UNC and RPCCC). Office 365 is rated for storage and sharing internally and externally for most classifications of UNC-Chapel Hill owned and managed information, including the type of information stored and shared by PCaP. This compliant secure folder was used for the transfer of the recruitment and re-contact dataset created specifically for the DoD-funded PCaP Financial Toxicity grant. This same mechanism will be utilized for re-deposit of updated data returned to the PCaP Central Database from LSUHSC following PCaP Financial Toxicity grant recruitment and data collection.

Data collected from PCaP research subject and their caregiver surveys including abstraction of PCaP medical records will be entered into Research Electronic Data Capture (REDCap). REDCap is a secure, HIPAA-complaint web application for building and managing online surveys and databases.

A PCaP research subject tracking database specific for the proposed research was developed at LSUHSC in REDCap that was based on and incorporated data received from UNC. Two Excel documents were received from UNC containing contact and demographic data for LSU and UNC PCaP research subjects, which were merged and imported into the REDCap tracking database. The tracking database will serve as monitoring dashboard for interviewers, since it allows us to keep track of call and data collection activities for all PCaP research subjects.

### Subtask 3 Perform continuous data quality control

Data use agreements were negotiated and executed between UNC and LSUHSC. Transfer from UNC of data for PCaP research subject tracking was completed and data were validated (see below).

## Y2 Progress

**Telephone and Online** REDCap has inbuilt validation features, so most of the data that were collected over the phone or online have been clean. Some of the inbuilt validation features include date structure, text only fields, and only one option from given choices can be selected. Questionnaires done online are reviewed for completeness and, if instruments are left blank, research subjects are contacted to complete the survey. Research subjects who open the link and submit the questionnaires in multiple parts created more than one record, which required that all parts of all questionnaires surveys to be combined to create a single record. PCaP ID is assigned and entered once online questionnaires are complete.

**Teleform** A quality control of the scanned questionnaires is done before exporting the data into .csv format. The number of scanned copies and number of data points are matched to ensure accurate data export. Most fields are double-checked manually during the process of form evaluation.

Once the questionnaire data gets to PCaP, they are checked for completeness, accuracy and uniformity, and scrubbed for duplicate records. Quality control reports are generated and returned to each site (NC, LA) for resolution. All questionnaire data are merged with PCaP baseline data for analysis once the data analyst confirms all quality control report issues have been resolved. Of the 206 questionnaires completed, 181 questionnaires have been completed QC and have had data entered.

Subtask 4 Perform statistical analysis of quality-controlled data

## Major Task 2 Data Reporting

Subtask 1 Produce annual progress reports for PCaP

### Y1 Progress

Year 1 progress report completed.

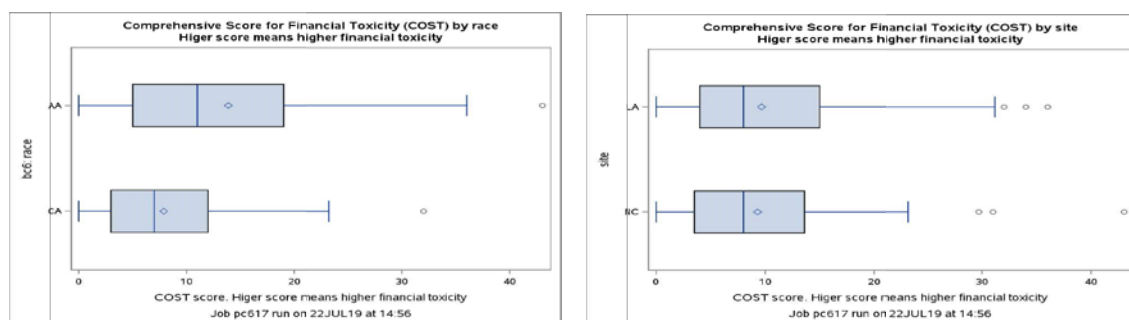
### Y2 Progress

Year 2 progress report completed.

Subtask 2 Produce manuscripts

### Y2 Progress

A very preliminary analysis compared financial distress (COST only) in research subjects (n= 194) by site (NC; n= 76 versus LA; n= 118) and by race (AA; n= 53 versus CA; n= 141).



**What opportunities for training and professional development has the project provided?**

Nothing to report

**How were the results disseminated to communities of interest?**

Nothing to report

**What do you plan to do during the next reporting period to accomplish the goals?**

**Y1 Progress**

Year 2 will focus on data collection. We are poised to contact living PCaP research subjects in both states. We are hiring the staff necessary to manage contact and conduct surveys of research subjects and their caregiver(s) and contact their treating physicians to obtain medical records for abstraction. Once underway and proceeding smoothly, we will adapt our process for living PCaP research subjects to approach the family, caregiver(s), and treating physician(s) of deceased PCaP research subjects to collect research data. Once medical record abstraction is underway and proceeding smoothly, we will hire the graduate research assistant at UNC and begin the updating of progression graphs on NC research subjects and construction of progression graphs on LA research subjects.

**Y2 Progress**

Year 3 will collect all questionnaire data on PCaP research subjects and their caregiver (if any), Q/C all data and begin its analysis, acquire oncologic outcome information (update treatments received and obtain most recent PSA values, and conduct the pilot “study-within-the-study” of the PCaP research subjects who die in the next year. Effort will be maintained at the current levels for Year 3 and funds will be sequestered for the anticipated effort needed in the no-cost extension period beginning July 2020 as outlined in the timeline in the revised Statement of Work to complete data analysis, produce manuscripts and prepare a new proposal to seek new funding for an intervention to address financial distress where financial distress is most problematic.

**4. IMPACT:**

**What was the impact on the development of the principal discipline(s) of the project?**

Nothing to report

**What was the impact on other disciplines?**

Nothing to report

**What was the impact on technology transfer?**

Nothing to report

**What was the impact on society beyond science and technology?**

Nothing to report

**5. CHANGES/PROBLEMS:**

**Changes in approach and reasons for change**

## **Y2 Progress**

The updating of oncologic outcome graphs on NC research subjects and the construction of oncologic outcome graphs on LA research subjects will require identification of treating primary care physicians for Research Subjects discharged from specialty oncologic follow-up and identification of specialty physicians providing oncologic care (urologist, radiation oncologist or medical oncologist) for 1616 research subjects. The continuing evolution in clinical data availability may allow more efficient collection of these data. We have initiated a pilot project of 20 NC research subjects and 20 LA research subjects to determine how much oncologic outcome data can be acquired electronically. In LA, PCaP research subjects are flagged already in SEER. Dr. Peters is meeting with SEER officials to determine if we can conduct a pattern-of-care study to identify treatments received, oncologic status, and interval PSA results. In NC, Dr. Bensen will explore the use of the UNC Tumor Registry and an ongoing UNC project to access claims data for research use, which should include data from NC research subjects who have BC/BS, Medicare or Medicaid.

## **Actual or anticipated problems or delays and actions or plans to resolve them**

### **Y1 Progress**

DoD IRB approval was not secured until 07/02/2018 for the reasons described above. Time between the probable notice of award 02/07/2017 and IRB approval 07/02/2018 was utilized to adapt the survey tools, create a project space within the PCaP Central Database, update PCaP research subject vital status, and prepare for data exchange between LSUHSC and UNC. PCaP research subjects could not be contacted and the staff could not be hired who are necessary to manage contact and conduct surveys of research subjects and their caregiver(s) and contact their treating physicians to obtain medical records for abstraction. The approved Statement of Work (Appendix 4) has been revised (Appendix 5) to reflect a reordering of work that is still accomplished within the 3 year funding period. However, the compression of data acquisition and analysis and reporting into 2 years is unrealistic. A further revision will most likely be necessary to extend “Major Task 2 Data Reporting Subtask 2 Produce manuscripts” from year 3 to year 4 in a no-cost extension.

### **Y2 Progress**

The LSUHSC IRB raised an issue about the “study-within-a-study.” The families of deceased PCaP Research Subjects would fall into 1 of 2 categories: dead of prostate cancer (dead of disease [DOD]) or dead of other causes (DOC). The IRB asked how we could enroll the primary caregiver in a study when the PCaP research subject is deceased: how would that caregiver be identified; how could they be contacted; and how both either would pose a HIPAA risk that cannot be resolved. We have decided to obtain the primary caregiver from the research subject and enroll them as part of the current study. We will conduct the “study-within-a-study” of those family units where the PCaP research subject dies going forward. Hence, this portion of the proposed research will be converted to “pilot status” to accrue data as our PCaP research subjects succumb DOD or DOC. The current data suggests that PCaP Research Subjects are dying in a ratio of about 4 to 1 (DOC vs DOD) and at a rate of about 80 per year. Hence, during the last 2 years of the proposed study (Year 3 and a no-cost extension Year 4), we should enroll a pilot group of approximately 160 families who suffered the loss of about 128 men from DOC versus 32 men from DOD.

## **Changes that had a significant impact on expenditures**

### **Y1 Progress**

The delay in securing DoD IRB approval until 07/02/2018 produced a delay in hiring study personnel that has moved Year 1 funds in to Year 2. Further adjustments may be necessary since the revised timeline (see revised statement of work) is ambitious.

## **Y2 Progress**

We propose an additional revision of our timeline (Statement of Work) due to the delay in securing DoD IRB approval until 07/02/2018 that produced a delay in hiring study personnel that in turn moved Year 1 funds in to Year 2. We have now moved year 2 funds in to Year 3 and will have funds left over to fund a Year 4 no cost extension, if approved. We are in the midst of very successful data collection that make it highly likely that we will meet all the goals of the study.

## **Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents**

None

## **6. PRODUCTS:**

### **Publications, conference papers, and presentations**

Nothing to report

### **Journal publications**

Nothing to report

### **Books or other non-periodical, one-time publications**

Nothing to report

### **Other publications, conference papers, and presentations**

Nothing to report

### **Technologies or techniques**

Nothing to report

### **Inventions, patent applications, and/or licenses**

Nothing to report

### **Other Products**

Nothing to report

## **7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS**

### **What individuals have worked on the project?**

## **Y1 Progress**

Name: James L. Mohler

Project Role: Principal Investigator

Research Identifier: ORCID ID: 0000-0002-7726-3795

Nearest person month worked: 1

Contribution to project: No change- Dr. Mohler will serve as the Principal Investigator. He will be responsible for project initiation (7% Y1), project oversight and annual progress report generation (3% Y1-3), clinical graph quality (10% Y2), data analysis oversight (2% Y1-3) generation of 4 manuscripts (15% Y3). Dr. Mohler will be responsible for the overall scientific integrity, management and reporting of results. He will interact with Drs. Bensen and Peters at UNC and LSUHSC, respectively. He will serve as a resource to Dr. Peters for clinical issues and to Dr. Bensen for PSA measurement and treatment graphing. He will continue to oversee all immunohistochemistry, visual scoring and image analysis.

Funding Support: National Cancer Institute, National Institute of Diabetes and Digestive and Kidney Diseases, Department of Defense

Name: Jeannette T. Bensen

Project Role: Co-Investigator

Research Identifier: ORCID ID: 0000-0003-4972-0087

Nearest person month worked: 1

Contribution to project: No change- Dr. Bensen will oversee and facilitate data collection and distribution, and assist in interpretation of the follow-up data for PCaP research subjects in North Carolina. Dr. Bensen will assist in preparation of the 4 planned study-related manuscripts. She, Dr. Mohler and Dr. Bensen's graduate research assistant, assisted by Mr. Gerstel, will construct the CaP disease status/treatment graphs (update those made already for NC research subjects and construct graphs for LA research subjects). Dr. Bensen will coordinate all UNC-based aspects of the study. She will join Drs. Mohler and Peters in quarterly teleconferences that will occur during Dr. Mohler's quarterly visits mostly to LSUHSC but occasionally, especially in Year 3, to UNC.

Funding Support: NIH/National Human Genome Research Institute, University Cancer Research Fund (North Carolina), NIH/National Institute of Environmental Health Sciences, National Cancer Institute

Name: Edward Peters

Project Role: Co-Investigator

Research Identifier: ORCID ID: 0000-0003-4928-6532

Nearest person month worked: 1

Contribution to project: No change- Dr. Peters will supervise all EDC research staff and closely coordinate with Drs. Mohler and Bensen to ensure the successful execution, validity and integrity of the study aims. Dr. Peters will be responsible for assuring that subject recontact, data collection, data processing and data linkage are conducted properly through the EDC. He also is an Epidemiologist with the Louisiana State Tumor Registry and will liaison with Louisiana State Tumor Registry staff to ensure appropriate follow-up, outcome and clinical linkages are made for LA research subjects. He will be available for weekly staff project meetings and assure that quality control procedures for data collection are followed, and sufficient EDC resources are available at all times for the project.

Dr. Peters will provide monthly status reports of case contact and data collection as well as address any study-related issues with Drs. Mohler and Bensen. Dr. Peters will be available to Dr. Mohler to coordinate all LSUHSC-based aspects of the study. He will join Drs. Mohler and Bensen in quarterly teleconferences that will occur during Dr. Mohler's quarterly visits mostly to LSUHSC but occasionally, especially in Year 3, to UNC.

Funding Support:

Name: Laura Farnan

Project Role: Other, Biostatistician

Research Identifier: ORCID ID: 0000-0001-9240-4974

Nearest person month worked: 1

Contribution to project: No change- Dr. Farnan will organize data and quality control in Years 1 and 2. She will analyze data and participate in preparation of the 4 manuscripts in Year 3.

Funding Support: University Cancer Research Fund (North Carolina)

## Other Personnel

KC Madhav                      2 calendar months

## Y2 Progress

Name: James L. Mohler

Project Role: Principal Investigator

Research Identifier: ORCID ID: 0000-0002-7726-3795

Nearest person month worked: 1

Contribution to project: No change- Dr. Mohler will serve as the Principal Investigator. He will be responsible for project initiation (7% Y1), project oversight and annual progress report generation (3% Y1-3), clinical graph quality (perhaps now 5% Y3 and 5% Y4), data analysis oversight (perhaps now 2% Y1-4) generation of 4 manuscripts (perhaps now 5% Y3 and 10% Y4). Dr. Mohler will be responsible for the overall scientific integrity, management and reporting of results. He will interact with Drs. Bensen and Peters at UNC and LSUHSC, respectively. He will serve as a resource to Dr. Peters for clinical issues and to Dr. Bensen for PSA measurement and treatment graphing.

Funding Support: National Cancer Institute, National Institute of Diabetes and Digestive and Kidney Diseases, Department of Defense

Name: Jeannette T. Bensen

Project Role: Co-Investigator

Research Identifier: ORCID ID: 0000-0003-4972-0087

Nearest person month worked: 1

Contribution to project: No change- Dr. Bensen will oversee and facilitate data collection and distribution, and assist in interpretation of the follow-up data for PCaP research subjects in North Carolina. Dr. Bensen will assist in preparation of the 4 planned study-related manuscripts. She, Dr. Mohler and Dr. Bensen's graduate research assistant, assisted by Mr. Gerstel, will construct the CaP disease status/treatment graphs (update those made already for NC research subjects and construct graphs for LA research subjects). Dr. Bensen will coordinate all UNC-based aspects of the study. She will join Drs. Mohler and Peters in quarterly teleconferences that will occur during Dr. Mohler's quarterly visits mostly to LSUHSC but occasionally, especially in Year 3 or 4, to UNC.

Funding Support: NIH/National Human Genome Research Institute, University Cancer Research Fund (North Carolina), NIH/National Institute of Environmental Health Sciences, National Cancer Institute, Department of Defense

Name: Edward Peters

Project Role: Co-Investigator

Research Identifier: ORCID ID: 0000-0003-4928-6532

Nearest person month worked: 1

Contribution to project: No change- Dr. Peters will supervise all EDC research staff and closely coordinate with Drs. Mohler and Bensen to ensure the successful execution, validity and integrity of the study aims. Dr. Peters will be responsible for assuring that subject recontact, data collection, data processing and data linkage are conducted properly through the EDC. He also is an Epidemiologist with the Louisiana State Tumor Registry and will liaison with Louisiana State Tumor Registry staff to ensure appropriate follow-up, outcome and clinical linkages are made for LA research subjects. He will be available for weekly staff project meetings and assure that quality control procedures for data collection are followed, and sufficient EDC resources are available at all times for the project.

Dr. Peters will provide monthly status reports of case contact and data collection as well as address any study-related issues with Drs. Mohler and Bensen. Dr. Peters will be available to Dr. Mohler to coordinate all LSUHSC-based aspects of the study. He will join Drs. Mohler and Bensen in quarterly teleconferences that will occur during Dr. Mohler's quarterly visits mostly to LSUHSC but occasionally, especially in Year 3 or 4, to UNC.

Funding Support: Department of Defense, National Cancer Institute

Name: Laura Farnan

Project Role: Other, Biostatistician

Research Identifier: ORCID ID: 0000-0001-9240-4974

Nearest person month worked: 1

Contribution to project: No change- Dr. Farnan will organize data and quality control in Years 1, 2 and 3. She will analyze data and participate in preparation of the 4 manuscripts in Years 3 and 4.

Funding Support: University Cancer Research Fund (North Carolina), NIH/National Human Genome Research Institute, Department of Defense

**Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**

#### **Y1 Progress**

Yes, active other supports for Dr. James L. Mohler, Dr. Jeannette Bensen, and Dr. Edward Peters were updated below. Nothing to report for Dr. Laura Farnan.

#### **Changes in active support**

##### **MOHLER, JAMES L.**

##### **Pending to active**

**Title:** Genetic and Epigenetic Prostate Cancer Related alterations in early onset disease in African American Men (Woloszynska-Read)

**Time Commitments:** 1.20 calendar months

**Supporting Agency:** DoD

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:** Department of Defense, USA MED RESEARCH ACQ ACTIVITY 820 CHANDLER ST FORT DETRICK MD 21702-5014/ LYMOR BARNHARD

**Performance Period:** 04/01/2017-03/31/2020

##### **Level of funding:**

**Brief description of project's goals:** Proposed research aims to identify molecular alterations that distinguish aggressive forms of early onset prostate cancer commonly found in African-American men will contribute to the development of African American tumor (epi)genetic signature(s) and ultimately will lead to personalized medicine strategies for this group of patients.

##### **List of specific aims:**

1. Determine the relative frequency of genetic lesions found in PCa in AAs and EAs.
2. Determine novel, clinically relevant methylomic and transcriptomic differences in PCa from AAs and EAs Obtain and link vital status data and cause of death in PCaP research subjects

**Overlap:** None

**Active to completed**

**Title:** Prostate Cancer: Transition to Androgen Independence, Project 1: Interference with the Androgen Receptor and Its Ligands in Recurrent Prostate Cancer (French - PI)

**Time Commitments:** 0.60 calendar months

**Supporting Agency:** National Cancer Institute P01-CA77739

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:**

Mark Kramer, Administrative Director, UNC Lineberger Comprehensive Cancer Center Campus Box 7295 102 Mason Farm Road, Chapel Hill, NC 27599-7295,

**Performance Period:** 04/01/2005-03/31/2017 (NCE)

**Level of Funding:**

**Brief description of project's goals:** Renewal of a project that tests the hypothesis that recurrence of prostate cancer during androgen deprivation therapy can be prevented or delayed by preventing the accumulation of tissue androgens and/or inhibiting the androgen receptor.

**List of specific aims:**

1. Prevent the changes in androgen metabolism that provide AR ligand(s) in the immediate post-castration period
2. Degrade AR ligand(s) formed in the immediate post-castration period
3. Diminish or eliminate AR in the immediate post-castration period

**Overlap:** None

**Title:** Diet changes among prostate cancer patients under expectant management (Marshall - PI)

**Time Commitments:** 0.60 calendar months

**Supporting Agency:** National Cancer Institute

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:** Program Official:

Howard L. Parnes,

**Performance Period:** 09/28/2009-01/31/2017 (NCE)

**Level of Funding:**

**Brief description of project's goals:** The focus of this study is to assess whether a diet emphasizing plant consumption decreases the probability that low grade, low-volume prostate cancer (LGLV) in expectant management (EM) patients progresses to a more aggressive form of cancer that merits active treatment. The intervention will be conducted through one of the leading cooperative oncology research groups: Cancer and Leukemia Group B (CALGB).

**List of specific aims:**

1. Assess the effect of a telephone-based dietary intervention on PSA, PSA doubling time, Gleason score and tumor extension in LGLV prostate cancer patients treated with EM.
2. Assess the effect of a telephone-based dietary intervention on treatment seeking, anxiety and coronary heart disease in prostate cancer patients treated with EM.

**Overlap:** None

**Title:** Deprive prostate cancer of DHEAS to prevent castration-recurrent prostate cancer (Wu – PI)

**Time Commitments:** 0.12 calendar months

**Supporting Agency:** NIH/NCI 1R21CA191895-01 **Name and address of the Funding Agency's Procuring Contracting/Grants Officer:** Viviana Knowles, 9609 Medical Center Drive, West Tower, Bethesda, MD 20892

**Performance Period:** 09/17/2014-02/28/2018 (NCE)

**Level of Funding:**

**Brief description of project's goals:** This research seeks to address the racial differences in prostate cancer aggressiveness from a biological perspective.

**List of specific aims:**

1. Characterize the expression of STS and potential STS regulators in CRPC

2. Evaluate the value of targeting DHEAS usage by prostate cancer cells to prevent post-castration tumor growth

3. Identify DHEAS uptake mechanisms

**Overlap:** None

**BENSEN, JEANNETTE T.**

**Pending to active**

**Title:** North Carolina Clinical Genomic Evaluation by Next-Gen Exome Sequencing 2

**Time commitment:** 7.20 calendar months

**Supporting Agency:** NIH, National Human Genome Research Institute (NHGRI)

**Name and Address of the Funding Agency Procuring Contracting/Grants Officer:** Unavailable

**Performance Period:** 08/01/17-05/31/21

**Level of Funding:**

**Brief description of projects goals:**

NCGENES 2 will generate the necessary evidence to support the use of Whole Exome Sequencing (WES) as a standard tool in the management of patients with genetic disorders and enable its implementation in populations that experience health disparities.

**Overlap:** None

**FARNAN, LAURA**

Nothing to report

**PETERS, EDWARD S.**

**Pending to active**

**Title:** Mid-South Transdisciplinary Collaborative Center for Health Disparities Research

**Time Commitments:** 1.2 calendar

**Supporting Agency (and grant #):** NIH 4U54MD008176

**Address:**

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:**

**Performance Period:** 8/1/2016-7/31/2018

**Level of Funding:**

**Project Goals:** Test the feasibility of recruitment and participation of our population into a trial of a mindfulness training using a novel smartphone application (HeadSpace), which integrates mindfulness training cues and assessment, and determine whether it improves trait mindfulness.

**List of specific aims:**

1. To estimate changes in mindfulness practice from baseline to follow-up

**Overlap:** None

**Active to completed**

**Title:** Women and their Children's Health Study, Trapido (PI), Peters (Co-PI)

**Time Commitments:** 1.08 calendar

**Supporting Agency (and grant #):** NIH/NIEHS 1U01ES021497-01

**Address:**

National Institute of Environmental Health Sciences

P.O. Box 12874

Research Triangle Park, North Carolina USA 27709

**Contracting/Grants Officer:** Donald Ellis

**Performance Period:** 6/27/11-4/30/2017

**Level of Funding:**

**Project Goals:** A network of researchers will evaluate potential harmful effects of the Deepwater Horizon disaster on reproduction and birth outcomes, the cardiorespiratory system, cancer, and other chronic diseases as well as behavior and mental health. The network will conduct research to evaluate the level of potentially harmful contaminants in air, water, and seafood, and assess their relationship to health outcomes.

**List of specific aims:**

1. To establish a prospective cohort study population representing the women and children living in seven parishes heavily affected by the Deepwater Horizon oil spill. This cohort will be an extremely valuable and unique resource for future investigations and collaborations to examine the health effects associated with a massive oil spill.
2. To examine among the adult women the association between seafood consumption and heavy metal accumulation (i.e. arsenic, cadmium, chromium, nickel, manganese and lead) measured in participants' urine. Further to examine whether heavy metal accumulation is associated with a greater presence of neurological, respiratory or immunologic disorders at baseline and prospectively.
3. To estimate among adult women the association between oil spill exposure and physical and emotional health outcomes such as respiratory disease, rashes, headaches, depression and emotional distress, controlling for potential confounders. In addition, to assess whether this relationship is modified by estimates of community and individual resilience and social capital.
4. To identify and enroll the study population for the Assessment of Community Stressors on Children sub-study (Columbia University-David Abramson). The overall goals of this project are to: (1) understand the impacts of the Deepwater Horizon oil spill on children's development and well-being, and (2) examine how parental and social forces, and alternative treatment models, can mediate or modify the spill's effects on children.

**Overlap:** None

**Title:** Reassessment of Monitoring the Impact of a Prophylactic HPV Vaccine on HPV Types in Cancers Using Tissues from Central Cancer, Peters (PI)

**Time Commitments:** 0.9 calendar

**Supporting Agency:** Centers of Disease Control and Prevention (via Battelle)

**Address:**

1100 Dexter Ave N, Suite 400  
Seattle, WA 98109

**Contracting/Grants Officer:** April Greek

**Performance Period:** 01/1/17-12/31/17

**Level of Funding:**

**Project Goals:** To measure the HPV prevalence and type distribution among a sample of HPV associated cancers 10 years after the baseline initial effort

**List of specific aims:**

1. To re-establish the infrastructure for the systematic monitoring of HPV types in cervical and other HPV-associated cancers;
2. Using infrastructure to type HPV distribution of cervical cancer and other HPV-associated cancer cases from participating population-based central cancer registries for 2014-2015.

**Overlap:** None

**Title:** Patient Generated Health Data (PGHD) to Enhance SEER Data Collection, Peters (PI)

**Time Commitments:** 1.0 calendar

**Supporting Agency (and grant #):** NIH/SEER H HHSN261201300016I/HHSN26100015I

**Address:**

National Cancer Institute/ OA  
9609 Medical Center Drive  
Bethesda, MD 20892

**Contracting/Grants Officer:** William Neal

**Performance Period:** 9/19/16-9/18/17

**Level of Funding:**

**Project Goals:** To develop the requisite infrastructure using smartphone based technology to capture patient generated health data to assess treatment adherence, social support, stress and other psychosocial characteristics in cancer survivors.

**List of specific aims:**

1. To assess the feasibility of PGHD methods to serve as a complement to traditionally collected registry data, focusing on patients' personal experiences in adhering to cancer treatment as a starting point for this evaluation.
2. To investigate the feasibility of collecting PGHD at a minimum of two points in time, for a longitudinal view of patients' personal experiences in adhering to cancer treatment regimens.
3. To provide value back to patients by offering reports or journaling capabilities as a record of personal experiences during treatment
4. To generate knowledge on best practices, costs, and benefits for utilizing PGHD methodologies in the context of cancer treatment surveillance.

**Overlap:** None

**Title:** SEER Linked Virtual Tissue Repository, Wu (PI)

**Time Commitments:** 0.24 calendar months

**Supporting Agency:** NIH/NCI/SEER NHHSN2612013000161

**Address:**

National Cancer Institute / OA

9609 Medical Center Dr.

RM#1E160, MSC 9705

**Contracting/Grants Officer:**

Marla Jacobsen

**Performance Period:** 9/172015-9/16/2017

**Level of Funding:**

**Project goals:** To develop and test the capacity of a SEER Registry to establish a virtual biospecimen locator service to provide high quality annotated cancer specimens for molecular epidemiologic investigations.

**List of specific aims:**

1. To assess the ability of Louisiana Tumor Registry to serve as a resource for biospecimen research as a SEER Contractor Registry.
2. To locate cases with biospecimens in pathology laboratories in Louisiana and for the LTR to retrieve those biospecimens as a resource for future biospecimen research.
3. To provide custom annotation of specimens.
4. To assess availability of tissue blocks from subjects with pathology reports meeting inclusion criteria.
5. To secure tissue blocks slated for destruction that meet study eligibility criteria.

**Overlap:** None

**Title:** National Comprehensive Cancer Control Program, Wu (PI )

**Time Commitments:** 0.5 calendar months

**Supporting Agency (and grant #):** CDC/NPRC

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:**

Olivia Maar

**Performance Period:** 6/30/20012-6/29/2017

**Level of Funding:**

**Brief description of project's goals:** The major goal of this project was to conduct population based cancer surveillance in Louisiana.

**Overlap:** None

## Y2 Progress

Yes, other supports for Dr. Jeannette Bensen, Dr. Edward Peters and Dr. Laura Farnan were updated below. Dr. James Mohler had no changes.

### BENSEN, JEANNETTE

#### Active to Completed

**Title:** UNC Cancer Survivorship Cohort (Bensen- PI)

**Time commitment:** 9 Calendar months

**Supporting Agency:** University Cancer Research Fund - NC State Funding

**Name and Address of the Funding Agency Procuring Contracting/Grants Officer:**

Unavailable

**Performance Period:** 4/1/17 - 3/31/18

**Level of Funding:**

**Brief description of projects goals:**

The main goals of this application are to expand and enhance this large novel and ethnically diverse adult cancer cohort to 10,000 cancer survivors with comprehensive data collection and follow-up, maintain extensive infrastructure that links clinical, biospecimen and patient -reported outcomes, and to create novel data linkages to facilitate research on critical cancer survivorship issues.

**Specific Aims:**

1. Create a large, well-characterized cohort of adult cancer survivors that includes biospecimens, medical history and patient interview data
2. Understand long-term effects of cancer, evaluate interventions to reduce adverse symptoms, assess the burden of comorbid conditions, examine treatment side effects, and improve the cost-effectiveness of survivorship care and services.
3. Determine the impact of racial and economic disparities, investigate genetic predisposition that may influence treatment efficacy, toxicity, and survival, and improve the quality of life (QoL) of cancer survivors

**Overlap:** None

### PETERS, EDWARD S.

#### New to Current

**Title:** Louisiana Rural Oral Health Network Peters (Co-PI)

**Time Commitments:** 0.5 calendar months

**Supporting Agency (and grant #):** HRSA (P10RH32093)

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:**

Sara Afayee

Federal Office of Rural Health Policy

Health Resources and Services Administration (HRSA)

U.S. Department of Health and Human Services

5600 Fishers Lane - 17W49C Rockville, MD 20857

**Performance Period:** 8/1/2018-7/31/2020

**Level of Funding:**

**Brief description of project's goals:** The goals of this project is to establish the infrastructure to support and sustain a rural oral health network (LaROHN), complete a Community Oral Health Needs Assessment, and assess service delivery models that will be used to address identified needs

**List of specific aims:**

1. Undertake a Community Rural Oral Health Needs Assessment;

2. Evaluate potential service delivery models and study policy that would be necessary for successful implementation of selected models.

**Overlap:** None

**Title:** Surveillance, Epidemiology and End Results (SEER) Program Wu (PI)

**Time Commitments:** 0.6 calendar

**Supporting Agency (and grant #):** NIH/NCI/SEER HHSN261201800007I/HHSN26100002 (P00001)

**Address:**

National Institutes of Health  
National Cancer Institute  
Bethesda, MD 20892-7511

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:**

John O. Turner

**Performance Period:** 5/1/2019-4/30/2028

**Level of Funding:**

**Project Goals:** The major goal of this project is to conduct population based cancer surveillance in Louisiana

**Specific Aims:**

1. Assemble and report, on a periodic basis, estimates of cancer incidence.
2. Monitor annual cancer incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups defined by geographic, demographic, and social characteristics.
3. Provide continuing information on changes over time in extent of disease at diagnosis, trends in therapy, and changes in cancer patient survival.
4. Identify the occurrence of possible iatrogenic cancers, i.e., cancers that are caused by cancer therapy.
5. Serve as a research resource to the National Cancer Institute, and conduct studies dealing with current cancer control issues as well as issues related to the operation of the SEER Program which may lead to improved and/or more cost-effective operating procedures.

**Overlap:** None

## **New to Completed**

**Title:** Mid-South Transdisciplinary Collaborative Center for Health Disparities Research

**Time Commitments:** 1.2 calendar

**Supporting Agency (and grant #):** NIH 4U54MD008176

**Address:**

**Name and address of the Funding Agency's Procuring Contracting/Grants Officer:**

**Performance Period:** 8/1/2016-7/31/2018

**Level of Funding:**

**Project Goals:** Test the feasibility of recruitment and participation of our population into a trial of a mindfulness training using a novel smartphone application (HeadSpace), which integrates mindfulness training cues and assessment, and determine whether it improves trait mindfulness.

**Specific Aims:** To estimate changes in mindfulness practice from baseline to follow-up.

**FARNAN, L.**

## **Active to Completed**

**Title:** UNC Cancer Survivorship Cohort (Bensen- PI)

**Time commitment:** 12 Calendar months (100.00%)

**Supporting Agency:** University Cancer Research Fund - NC State Funding

**Name and Address of the Funding Agency Procuring Contracting/Grants Officer:**

Unavailable

**Performance Period:** 4/1/17 - 3/31/18

**Level of Funding:**

**Brief description of projects goals:**

The main goals of this application are to expand and enhance this large novel and ethnically diverse adult cancer cohort to 10,000 cancer survivors with comprehensive data collection and follow-up, maintain extensive infrastructure that links clinical, biospecimen and patient -reported outcomes, and to create novel data linkages to facilitate research on critical cancer survivorship issues.

**Specific Aims:**

1. Create a large, well-characterized cohort of adult cancer survivors that includes biospecimens, medical history and patient interview data
2. Understand long-term effects of cancer, evaluate interventions to reduce adverse symptoms, assess the burden of comorbid conditions, examine treatment side effects, and improve the cost-effectiveness of survivorship care and services.
3. Determine the impact of racial and economic disparities, investigate genetic predisposition that may influence treatment efficacy, toxicity, and survival, and improve the quality of life (QoL) of cancer survivors

**Overlap:** None

**What other organizations were involved as partners?**

Nothing to report

## **8. SPECIAL REPORTING REQUIREMENTS**

**COLLABORATIVE AWARDS:**

Nothing to report

## **9. APPENDICES:**

**Y1 Progress**

1. Survey Instrument: Research Subject
2. Survey Instrument: Caregiver(s)
3. Medical Record Abstraction (MRA)
4. Statement of Work: Approved
5. Statement of Work: Revised (2018)

**Y2 Progress**

6. Survey Instrument: Research Subject, Telephone-based
7. Survey Instrument: Research Subject, Web-based
8. Survey Instrument: Research Subject, Paper-based
9. Statement of Work: Revised (2019)

# Tracking

Record ID

---

Today's date

---

Date of invitation letter sent?

---

Mail returned by USPS?

- ☐ Yes  
☐ No

Any update on participant's address?

- ☐ Yes  
☐ No

Address

---

City

---

State

---

Zip

---

Pre-paid mail returned?

- ☐ Yes  
☐ No

Who returned the pre-paid mail?

- ☐ Participant  
☐ Spouse  
☐ Other

Specify

---

Any update on participant's existing contact information?

- ☐ Yes  
☐ No

If yes, please update

- ☐ Home address  
☐ Cell phone number  
☐ Home phone number  
☐ Email address

Address

---

City

---

State

---

---

Zip

---

---

Cell Phone

---

---

Home Phone

---

---

Email address

---

---

Update on vital status?

- ☐ Yes  
☐ No

---

Deceased or alive?

- ☐ Deceased  
☐ Living

---

**Telephone Call to Participant**  
**FIRST CALL**

---

---

Who is conducting phone survey?

- ☐ Alexandra Lieberman  
☐ Ashley Fenton  
☐ Hasheemah Afaneh  
☐ Sydney Santa Ana  
☐ Cameron Barney

---

Phone number called

---

---

Call Date and Time

---

---

Response

- ☐ Answered by participant  
☐ Answered by someone else  
☐ Not answered  
☐ Wrong phone number

---

Does participant want to do the interview now?

- ☐ Yes  
☐ No

---

Interview start time

---

---

Interview end time

---

---

If no, please specify the reasons

- ☐ Wants to reschedule for next date/time  
☐ Doesn't want to participate in the study  
☐ Wants to complete the survey via email  
☐ Wants mail survey

---

If answered by someone else, ask contact details of the participant

---

---

If rescheduled, what date and time?  
(Also update your calendar)

---

---

Reasons to decline?

---

---

CONFIRMATION OF DECLINE OF PARTICIPATION

- ☐ Participation decline  
☐ Participation not decline

---

If deceased, date of deceased?

---

---

Primary cause of death

---

---

Left voicemail?

- ☐ Yes  
☐ No

---

Did study participant call us?

- ☐ Yes  
☐ No

---

Call Notes

---

---

Call Purpose (Call #2)

- ☐ Not answered last time  
☐ Calling on different phone number  
☐ Rescheduled to this time to do interview  
☐ Unavailable on previous call

---

Who is conducting phone survey?

- ☐ Alexandra Lieberman  
☐ Ashley Fenton  
☐ Hasheemah Afaneh  
☐ Sydney Santa Ana  
☐ Cameron Barney

---

Phone number called

---

---

Call Date and Time

---

---

Response

- ☐ Answered by participant  
☐ Answered by someone else  
☐ Not answered  
☐ Wrong phone number

---

Does participant want to do the interview now?

- ☐ Yes  
☐ No

---

Interview start time

---

---

Interview end time

---

---

If no, please specify the reasons

☐ Wants to reschedule for next date/time  
☐ Doesn't want to participate in the study  
☐ Wants to complete the survey via email  
☐ Wants mail survey

---

If answered by someone else, ask contact details of the participant

---

If rescheduled, what date and time?  
(Also update your calendar)

---

Reasons to decline?

---

CONFIRMATION OF DECLINE OF PARTICIPATION

☐ Participation decline  
☐ Participation not decline

---

If deceased, date of deceased?

---

Primary cause of death

---

Left voicemail?

☐ Yes  
☐ No

---

Did study participant call us?

☐ Yes  
☐ No

---

Call Notes

---

Call Purpose (Call #3)

☐ Not answered last time  
☐ Calling on different phone number  
☐ Rescheduled to this time to do interview

---

Who is conducting phone survey?

☐ Alexandra Lieberman  
☐ Ashley Fenton  
☐ Hasheemah Afaneh  
☐ Sydney Santa Ana  
☐ Cameron Barney

---

Phone number called

---

Call Date and Time

---

Response

☐ Answered by participant  
☐ Answered by someone else  
☐ Not answered  
☐ Wrong phone number

---

Does participant want to do the interview now?

☐ Yes  
☐ No

---

---

Interview start time

---

---

Interview end time

---

---

If no, please specify the reasons

- ☐ Wants to reschedule for next date/time
- ☐ Doesn't want to participate in the study
- ☐ Wants to complete the survey via email
- ☐ Wants mail survey

---

If answered by someone else, ask contact details of the participant

---

---

If rescheduled, what date and time?  
(Also update your calendar)

---

---

Reasons to decline?

---

---

CONFIRMATION OF DECLINE OF PARTICIPATION

- ☐ Participation decline
- ☐ Participation not decline

---

Left voicemail?

- ☐ Yes
- ☐ No

---

Did study participant call us?

- ☐ Yes
- ☐ No

---

Call Notes

---

---

Call Purpose (Call #4)

- ☐ Not answered last time
- ☐ Calling on different phone number
- ☐ Rescheduled to this time to do interview

---

Who is conducting phone survey?

- ☐ Alexandra Lieberman
- ☐ Ashley Fenton
- ☐ Hasheemah Afaneh
- ☐ Sydney Santa Ana
- ☐ Cameron Barney

---

Phone number called

---

---

Call Date and Time

---

---

Response

- ☐ Answered by participant
- ☐ Answered by someone else
- ☐ Not answered
- ☐ Wrong phone number

---

Does participant want to do the interview now?

- ☐ Yes
- ☐ No

---

Interview start time

---

---

Interview end time

---

---

If no, please specify the reasons

- ☐ Wants to reschedule for next date/time
- ☐ Doesn't want to participate in the study
- ☐ Wants to complete the survey via email
- ☐ Wants mail survey

---

If answered by someone else, ask contact details of the participant

---

---

If rescheduled, what date and time?  
(Also update your calendar)

---

---

Reasons to decline?

---

---

CONFIRMATION OF DECLINE OF PARTICIPATION

- ☐ Participation decline
- ☐ Participation not decline

---

Left voicemail?

- ☐ Yes
- ☐ No

---

Did study participant call us?

- ☐ Yes
- ☐ No

---

Call Notes

---

---

Call Purpose (Call #5)

- ☐ Not answered last time
- ☐ Calling on different phone number
- ☐ Rescheduled to this time to do interview

---

Who is conducting phone survey?

- ☐ Alexandra Lieberman
- ☐ Ashley Fenton
- ☐ Hasheemah Afaneh
- ☐ Sydney Santa Ana
- ☐ Cameron Barney

---

Phone number called

---

---

Call Date and Time

---

---

Response

- ☐ Answered by participant
- ☐ Answered by someone else
- ☐ Not answered
- ☐ Wrong phone number

---

Does participant want to do the interview now?

- ☐ Yes
- ☐ No

---

Interview start time

---

---

Interview end time

---

---

If no, please specify the reasons

- ☐ Wants to reschedule for next date/time
- ☐ Doesn't want to participate in the study
- ☐ Wants to complete the survey via email
- ☐ Wants mail survey

---

If answered by someone else, ask contact details of the participant

---

---

If rescheduled, what date and time?  
(Also update your calendar)

---

---

Reasons to decline?

---

---

CONFIRMATION OF DECLINE OF PARTICIPATION

- ☐ Participation decline
- ☐ Participation not decline

---

Left voicemail?

- ☐ Yes
- ☐ No

---

Did study participant call us?

- ☐ Yes
- ☐ No

---

Call Notes

---

---

Call Purpose (Call #6)

- ☐ Not answered last time
- ☐ Calling on different phone number
- ☐ Rescheduled to this time to do interview

---

Who is conducting phone survey?

- ☐ Alexandra Lieberman
- ☐ Ashley Fenton
- ☐ Hasheemah Afaneh
- ☐ Sydney Santa Ana
- ☐ Cameron Barney

---

Phone number called

---

---

Call Date and Time

---

---

Response

- ☐ Answered by participant
- ☐ Answered by someone else
- ☐ Not answered
- ☐ Wrong phone number

---

Does participant want to do the interview now?

- ☐ Yes
- ☐ No

---

Interview start time

---

---

Interview end time

---

---

If no, please specify the reasons

- ☐ Wants to reschedule for next date/time  
☐ Doesn't want to participate in the study  
☐ Wants to complete the survey via email  
☐ Wants mail survey

---

If answered by someone else, ask contact details of the participant

---

---

If rescheduled, what date and time?  
(Also update your calendar)

---

---

Reasons to decline?

---

---

CONFIRMATION OF DECLINE OF PARTICIPATION

- ☐ Participation decline  
☐ Participation not decline

---

Left voicemail?

- ☐ Yes  
☐ No

---

Did study participant call us?

- ☐ Yes  
☐ No

---

Call Notes

---

---

Interview start time

---

---

Interview end time

---

---

Total number of calls

---

---

Online survey sent?

- ☐ Yes  
☐ No

---

Paper survey sent?

- ☐ Yes  
☐ No

---

Survey completion method

- ☐ Telephone survey  
☐ Online survey  
☐ Paper survey

## Pcap Followup Contact Info

---

Today's Date

---

---

Study site

- ☐ LA  
☐ NC

---

Contacted in f/u 2013/14?

- ☐ Yes  
☐ No

---

First name

---

---

Last name

---

---

Full Name

---

---

Race

- ☐ White  
☐ Black  
☐ Other

---

Address

---

---

City

---

---

State

---

---

Zipcode

---

---

Full Address

---

---

Participant's cell phone number

---

---

Participant's work phone number

---

---

Participant's home phone number

---

---

Contact person

---

---

Contact person's cell phone number

---

---

Contact person's home phone number

---

---

Contact person's home phone number

---

## Demographics

---

Has your address changed?

☐ Yes  
☐ No

---

Today's Date

---

---

User

---

---

Address

---

---

City

---

---

State	<div><div><input type="radio"/> Alabama</div><div><input type="radio"/> Alaska</div><div><input type="radio"/> Arizona</div><div><input type="radio"/> Arkansas</div><div><input type="radio"/> California</div><div><input type="radio"/> Colorado</div><div><input type="radio"/> Connecticut</div><div><input type="radio"/> Delaware</div><div><input type="radio"/> Florida</div><div><input type="radio"/> Georgia</div><div><input type="radio"/> Hawaii</div><div><input type="radio"/> Idaho</div><div><input type="radio"/> Illinois</div><div><input type="radio"/> Indiana</div><div><input type="radio"/> Iowa</div><div><input type="radio"/> Kansas</div><div><input type="radio"/> Kentucky</div><div><input type="radio"/> Louisiana</div><div><input type="radio"/> Maine</div><div><input type="radio"/> Maryland</div><div><input type="radio"/> Massachusetts</div><div><input type="radio"/> Michigan</div><div><input type="radio"/> Minnesota</div><div><input type="radio"/> Mississippi</div><div><input type="radio"/> Missouri</div><div><input type="radio"/> Montana</div><div><input type="radio"/> Nebraska</div><div><input type="radio"/> Nevada</div><div><input type="radio"/> New Hampshire</div><div><input type="radio"/> New Jersey</div><div><input type="radio"/> New Mexico</div><div><input type="radio"/> New York</div><div><input type="radio"/> North Carolina</div><div><input type="radio"/> North Dakota</div><div><input type="radio"/> Ohio</div><div><input type="radio"/> Oklahoma</div><div><input type="radio"/> Oregon</div><div><input type="radio"/> Pennsylvania</div><div><input type="radio"/> Rhode Island</div><div><input type="radio"/> South Carolina</div><div><input type="radio"/> South Dakota</div><div><input type="radio"/> Tennessee</div><div><input type="radio"/> Texas</div><div><input type="radio"/> Utah</div><div><input type="radio"/> Vermont</div><div><input type="radio"/> Virginia</div><div><input type="radio"/> Washington</div><div><input type="radio"/> West Virginia</div><div><input type="radio"/> Wisconsin</div><div><input type="radio"/> Wyoming</div></div>
-------	---

Zipcode

---

May we contact you by email?

- ☐ Yes
- ☐ No

Email

---

May we contact you by cell phone?

- ☐ Yes
- ☐ No

---

Phone number

---

---

May we contact you at work?

- ☐ Yes  
☐ No

---

Phone number

---

**Do you have a friend or relative who could help us get in touch with you if we have trouble reaching you in the future? If so, please write their name and other information below.**

First name

---

---

Last name

---

---

Home phone number

---

---

Cell phone number

---

---

Work phone number

---

---

Email

---

---

Can you please tell me your date of birth?

---

---

What is your current marital status?

- ☐ Married or Living as Married  
☐ Widowed  
☐ Separated  
☐ Divorced  
☐ Never married

---

Has your marital status changed since you were diagnosed with prostate cancer?

- ☐ Yes  
☐ No

---

What race do you consider yourself to be?

- ☐ White  
☐ Black  
☐ Other

---

Can you please specify your race?

---

---

Since our last interview, have you moved?

- ☐ Yes  
☐ No  
☐ I don't know

---

If yes, why did you move? Check ALL that apply.

- ☐ To live in a new or better house or location
- ☐ To be closer to my doctor or clinic
- ☐ To be closer to my family
- ☐ To be closer to my friends
- ☐ So I could get help with daily activities
- ☐ So I could get help with medical care
- ☐ So my wife or partner could get help with daily activities
- ☐ So my wife or partner could get medical care
- ☐ To cut costs
- ☐ Because I could not afford to pay my rent, mortgage, property taxes or other expenses
- ☐ I don't know
- ☐ Other

---

Please specify \_\_\_\_\_

---

Which of the following best describes where you live now?

- ☐ Your own home or apartment
- ☐ A relative's home or apartment
- ☐ A friend's home or apartment
- ☐ A continuing care facility where you are living independently
- ☐ A nursing home or other group facility where you get daily care and assistance
- ☐ A shelter
- ☐ A hospice
- ☐ Some other living arrangement
- ☐ I don't have a regular living place

---

Do you own or partly own the place where you live?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

How many other people live with you?

- ☐ I live alone
- ☐ 1
- ☐ 2
- ☐ 3 - 4
- ☐ 5 - 6
- ☐ 7 - 10
- ☐ More than 10
- ☐ I don't know

---

If you live with other people, what relation are they to you?

- ☐ Wife or Partner
- ☐ One or more dependent children
- ☐ One or more adult children
- ☐ Other relatives
- ☐ Friend(s)
- ☐ Paid caregiver(s)
- ☐ Other
- ☐ I don't know

**We would like to ask who has helped you with your care most?**

Name

---

Relationship

---

Address

---

City

---

State	<input type="radio"/> Alabama <input type="radio"/> Alaska <input type="radio"/> Arizona <input type="radio"/> Arkansas <input type="radio"/> California <input type="radio"/> Colorado <input type="radio"/> Connecticut <input type="radio"/> Delaware <input type="radio"/> Florida <input type="radio"/> Georgia <input type="radio"/> Hawaii <input type="radio"/> Idaho <input type="radio"/> Illinois <input type="radio"/> Indiana <input type="radio"/> Iowa <input type="radio"/> Kansas <input type="radio"/> Kentucky <input type="radio"/> Louisiana <input type="radio"/> Maine <input type="radio"/> Maryland <input type="radio"/> Massachusetts <input type="radio"/> Michigan <input type="radio"/> Minnesota <input type="radio"/> Mississippi <input type="radio"/> Missouri <input type="radio"/> Montana <input type="radio"/> Nebraska <input type="radio"/> Nevada <input type="radio"/> New Hampshire <input type="radio"/> New Jersey <input type="radio"/> New Mexico <input type="radio"/> New York <input type="radio"/> North Carolina <input type="radio"/> North Dakota <input type="radio"/> Ohio <input type="radio"/> Oklahoma <input type="radio"/> Oregon <input type="radio"/> Pennsylvania <input type="radio"/> Rhode Island <input type="radio"/> South Carolina <input type="radio"/> South Dakota <input type="radio"/> Tennessee <input type="radio"/> Texas <input type="radio"/> Utah <input type="radio"/> Vermont <input type="radio"/> Virginia <input type="radio"/> Washington <input type="radio"/> West Virginia <input type="radio"/> Wisconsin <input type="radio"/> Wyoming
Zip	<input type="text"/>
Email	<input type="text"/>
Home Phone	<input type="text"/>
Cell Phone	<input type="text"/>

---

How long have you known [caregiver\_1]?  
(In years)

---

(years)

---

On average, how many hours in a day does  
[caregiver\_1] spend taking care of you?

---

(hours)

---

How long has [caregiver\_1] been your care giver?

---

(years)

---

Did anyone else help you with your cancer care?

☐ Yes  
☐ No

---

Name

---

---

Relationship

---

---

Please select all types of care you get from your caregiver

- ☐ Help with activities of daily living such as: get in and out of beds, get dressed, get to and from the toilet.....
- ☐ Help with instrumental of activities of daily living such as: transportation, housework, grocery or other shopping, preparing meals, managing finances....
- ☐ Help with communicating with healthcare professionals, monitoring severity, and advocating.

## SF 12 Version2 Health Survey

**INSTRUCTIONS: Now, I am going to ask for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.**

In general, would you say your health is:

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

**The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, not limited at all

Climbing several flights of stairs

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, Not limited at all

**During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

Accomplished less than you would like

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Were limited in the kind of work or other activities

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

Accomplished less than you would like

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Were limited in the kind of work or other activities

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all  
☐ A little bit  
☐ Moderately  
☐ Quite a bit  
☐ Extremely

**These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

**How much of the time during the past 4 weeks...**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Charlson Comorbidity Index (CCI)

**I am going to list some health conditions. Please let me know if you have been diagnosed with any of these conditions.**

Comorbidity (Choose all that are present)

- ☐ Myocardial infarct (+1)
- ☐ Congestive heart failure (+1)
- ☐ Peripheral vascular disease (+1)
- ☐ Cerebrovascular disease (except hemiplegia) (+1)
- ☐ Dementia (+1)
- ☐ Chronic pulmonary disease (+1)
- ☐ Connective tissue disease (+1)
- ☐ Ulcer disease (+1)
- ☐ Mild liver disease (+1)
- ☐ Diabetes (without complications) (+1)
- ☐ Diabetes with end organ damage (+2)
- ☐ Hemiplegia (+2)
- ☐ Moderate or severe renal disease (+2)
- ☐ Solid tumor (non metastatic) (+2)
- ☐ Leukemia (+2)
- ☐ Lymphoma, Multiple myeloma (+2)
- ☐ Moderate or severe liver disease (+3)
- ☐ Metastatic solid tumor (+6)
- ☐ AIDS (+6)

Age

- ☐ 50 - 59 (+1)
- ☐ 60 - 69 (+2)
- ☐ 70 - 79 (+3)
- ☐ 80 - 89 (+4)
- ☐ 90 - 99 (+5)

Do you have any other health problems?

- ☐ Yes
- ☐ No

If yes, please specify

Charlson ME, Pompei P, Ales KL, MacKenzie CR, A new method of classifying prognostic comorbidity in longitudinal studies: development and validation, 373-383, (c) Elsevier (1987)  
Journal of Diseases Homepage <http://www.sciencedirect.com/science/journal/00219681> Additional information:  
SCORING-<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC545968/>

# Medical

## PSA

How long has it been since your last PSA test?

- ☐ Less than 1 month  
☐ 1 - 2 months  
☐ 3 - 4 months  
☐ 5 - 6 months  
☐ 7 - 8 months  
☐ 9 - 10 months  
☐ 11 - 12 months  
☐ 1 - 1-1/2 years  
☐ 1-1/2 - 2 years  
☐ More than 2 years  
☐ I don't know

Do you know if your PSA level was undetectable last time you were tested?

- ☐ Yes  
☐ No  
☐ I don't know

Do you remember the name of your doctor who did your last PSA test?

- ☐ Yes  
☐ No

Name of Doctor

\_\_\_\_\_

Do you remember the name of HOSPITAL where you had PSA test?

- ☐ Yes  
☐ No

Name of hospital/clinic or lab

\_\_\_\_\_

Do you remember the address of hospital where you had PSA test?

- ☐ Yes  
☐ No

Street

\_\_\_\_\_

City

\_\_\_\_\_

State

\_\_\_\_\_

Zip

\_\_\_\_\_

Since our last interview, have you been followed up regarding prostate cancer?

- ☐ Yes  
☐ No  
☐ I don't know

Can you please tell us the doctor's name?

\_\_\_\_\_

---

Hospital/Clinic Name

---

Street

---

City

---

State

---

Zip Code

---

If YES, what other kinds of doctors or health care professionals have you talked to about your prostate cancer or treatment? Check ALL that apply.

- ☐ A urologist  
☐ A radiation oncologist  
☐ A medical oncologist  
☐ I don't know  
☐ Other
- 

Please specify

**Please tell us who are you seeing for your primary health care.**

Name of Doctor

Name of clinic

Address of the clinic

City of clinic

State

Zip

Is this person monitoring your PSA?

- ☐ Yes  
☐ No

---

Since our last interview, have you had any of the following procedures or tests? Check ALL that apply.

- ☐ A trans-rectal ultrasound examination of your prostate
- ☐ MRI
- ☐ CT scan
- ☐ Bone scan
- ☐ I don't know
- ☐ None

---

Since our last interview, have you participated in any clinical trials to test new prostate cancer treatments?

- ☐ Yes, one clinical trial
- ☐ Yes, more than one clinical trial
- ☐ No
- ☐ I don't know

---

**DRE**

---

How long has it been since your last Digital Rectal Exam (DRE)?

- ☐ Less than 1 month
- ☐ 1 - 2 months
- ☐ 3 - 4 months
- ☐ 5 - 6 months
- ☐ 7 - 8 months
- ☐ 9 - 10 months
- ☐ 11 - 12 months
- ☐ 1 - 1-1/2 years
- ☐ 1-1/2 - 2 years
- ☐ More than 2 years
- ☐ I don't know

---

Since our last interview, have you had a follow-up biopsy of your prostate taken with a needle through your rectum?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

How long has it been since your last follow-up biopsy?

- ☐ Less than 1 month
- ☐ 1 - 2 months
- ☐ 3 - 4 months
- ☐ 5 - 6 months
- ☐ 7 - 8 months
- ☐ 9 - 10 months
- ☐ 11 - 12 months
- ☐ 1 - 1-1/2 years
- ☐ 1-1/2 - 2 years
- ☐ More than 2 years
- ☐ I don't know

---

Since our last interview, did you have to make a NEW decision about what to do about your prostate cancer? (This could be deciding whether to have a new kind of treatment, whether to keep having or stop treatment you were already having, etc.)

- ☐ Yes
- ☐ No
- ☐ I don't know

Since our last interview, between you and your doctor, who was mostly responsible for deciding what to do about your prostate cancer?

- ☐ I was mostly responsible for deciding what to do  
☐ My doctor and I were both responsible  
☐ My doctor was mostly responsible for deciding what to do  
☐ I don't know

**Since our last interview, how much do you agree or disagree with the following statements about the NEW treatment decisions you made? Please choose a number from 1 to 5, where 1 means you Strongly DISAGREE and 5 means you Strongly AGREE with the statement.**

	1 (Strongly Disagree)	2	3 ( Don't Agree or Disagree)	4	5 (Strongly Agree)
I had all the information I needed to make a decision about treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctors told me the whole story about side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew the right questions to ask the doctor about treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had enough time to make a decision about treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the treatment choices I made.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**The next questions are about your health and the quality of your life as a prostate cancer survivor. We know that many of these questions are personal, but your answers are important to help us understand why life is better for some men with prostate cancer than it is for others.**

Since our last interview, have you had any problems with urination?

- ☐ Yes  
☐ No  
☐ I don't know

If YES, have you had any of the problems listed below? Check ALL that apply.

- ☐ Difficulty passing urine  
☐ Frequent or urgent urination  
☐ Problems with leaking urine (incontinence)  
☐ Pain during urination  
☐ Blood in urine  
☐ I don't know  
☐ Other

Please specify

\_\_\_\_\_

Have you talked to a doctor about problems with urination since our last interview?

- ☐ Yes  
☐ No  
☐ I don't know

---

Since our last interview, have you had any problems  
with erections or your sexual function?

- ☐ Yes
- ☐ No
- ☐ I don't know

# Epic-26

## EPIC-26

**The Expanded Prostate Cancer Index Composite Short Form** This questionnaire is designed to measure Quality of Life issues in patients with Prostate cancer. To help us get the most accurate measurement, it is important that you answer all questions honestly and completely. Remember, as with all medical records, information contained within this survey will remain strictly confidential.

Over the past 4 weeks, how often have you leaked urine?

- ☐ More than once a day
- ☐ About once a day
- ☐ More than once a week
- ☐ About once a week
- ☐ Rarely or never

Which of the following best describes your urinary control during the last 4 weeks?

- ☐ No urinary control whatsoever
- ☐ Frequent dribbling
- ☐ Occasional dribbling
- ☐ Total control

How many pads or adult diapers per day did you use to control leakage during the last 4 weeks?

- ☐ None
- ☐ 1 per day
- ☐ 2 per day
- ☐ 3 or more per day

### How big a problem, if any, has each of the following been for you during the last 4 weeks?

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
Dripping or leaking urine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain or burning on urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bleeding with urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weak urine stream or incomplete emptying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Need to urinate frequently during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall, how big a problem has your urinary function been for you during the last 4 weeks?

- ☐ No problem
- ☐ Very small problem
- ☐ Small problem
- ☐ Moderate problem
- ☐ Big problem

**How big a problem, if any, has each of the following been for you?**

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
Urgency to have a bowel movement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Increased frequency of bowel movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control of your stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bloody stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abdominal/Pelvic/Rectal pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall, how big a problem have your bowel habits been for you during the last 4 weeks?

- ☐ No problem  
☐ Very small problem  
☐ Small problem  
☐ Moderate problem  
☐ Big problem

**How would you rate each of the following during the last 4 weeks?**

	Very poor to none	Poor	Fair	Good	Very good
Your ability to have an erection?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to reach orgasm (climax)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How would you describe the usual QUALITY of your erections during the last 4 weeks?

- ☐ None at all  
☐ Not firm enough for any sexual activity  
☐ Firm enough for masturbation and foreplay only  
☐ Firm enough for intercourse

How would you describe the FREQUENCY of your erections during the last 4 weeks?

- ☐ I NEVER had an erection when I wanted one  
☐ I had an erection LESS THAN HALF the time I wanted one  
☐ I had an erection ABOUT HALF the time I wanted one  
☐ I had an erection MORE THAN HALF the time I wanted one  
☐ I had an erection WHENEVER I wanted one

Overall, how would you rate your ability to function sexually during the last 4 weeks?

- ☐ Very poor  
☐ Poor  
☐ Fair  
☐ Good  
☐ Very good

---

Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?

- ☐ No problem  
☐ Very small problem  
☐ Small problem  
☐ Moderate problem  
☐ Big problem

---

**How big a problem during the last 4 weeks, if any, has each of the following been for you?**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
Hot flashes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breast tenderness/enlargement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change in body weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

Urinary Incontinence

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Urinary Obstructive/Irritative

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---

Bowel

---

---

Sexual

---

---

Hormonal

---

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Wei J, Dunn R, Litwin M, Sandler H, and Sanda M. "Development and Validation of the Expanded Prostate Cancer Index Composite (EPIC) for Comprehensive Assessment of Health-Related Quality of Life in Men with Prostate Cancer", Urology. 56: 899-905, 2000.

# Medical Expenditure Panel Survey (MEPS)

## Cancer History

Are you currently being treated for cancer - that is are you planning or recovering from cancer surgery, or receiving chemotherapy, radiation therapy, or hormonal therapy for your cancer?

☐ Yes ☐ No

To the best of your knowledge, are you now free of cancer?

☐ Yes ☐ No ☐ I don't know

About how long ago did you receive your last cancer treatment?

- ☐ Less than 1 year ago
- ☐ 1 year ago to less than 3 years ago
- ☐ 3 years ago to less than 5 years ago
- ☐ 5 years ago to less than 10 years ago
- ☐ 10 years ago to 20 years ago
- ☐ More than 20 years ago
- ☐ I have not been treated for cancer

Did a doctor or other health professional ever tell you that your cancer had come back?

☐ Yes ☐ No

What was the most recent year a doctor or health professional told you that your cancer had come back? \_\_\_\_\_

Is this the first time you have been treated for any type of cancer?

☐ Yes  
☐ No

## Changes to Your Work Schedule

At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business?

☐ Yes ☐ No

**These next questions ask about different ways cancer, its treatment, or the lasting effects of that treatment may have affected your work - that is, your hours, duties, or employment status.**

**As you answer these questions, please think about the entire time from when you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

---

At any time since your first cancer diagnosis, did you take extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

☐ Yes ☐ No

---

At any time since your first cancer diagnosis, did you ask for extended paid time off from work, unpaid time off, or a change in your hours, duties or employment status?

☐ Yes ☐ No

---

Did you ask for these work changes...

- ☐ Because of your cancer, its treatment or its lasting effects?  
☐ Some other reason

---

Did you ever take extended paid time off from work (vacation, sick time and/or disability leave)? By extended time off, we mean more than an occasional day off here and there.

☐ Yes  
☐ No

---

When did you take extended paid time off from work? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

What do you estimate was the total amount of extended paid time off from work that you took?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is your extended paid time off from work ongoing?

☐ Yes ☐ No

---

Did you ever take unpaid time off from work?

☐ Yes ☐ No

---

When did you take unpaid time off from work? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

What do you estimate was the total amount of unpaid time off from work that you took?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is your unpaid time off ongoing?

☐ Yes  
☐ No

---

Did you ever change from working part-time to working full-time?

- ☐ Yes  
☐ No

---

When did you change from working part-time to working full-time? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

What do you estimate was the total amount of time you worked full-time?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes ☐ No

---

Did you ever change from working full time to working part-time?

- ☐ Yes ☐ No

---

When did you change from working full-time to working part-time? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

What do you estimate was the total amount of time you worked part-time?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes ☐ No

---

Did you ever change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day-to-day?

- ☐ Yes  
☐ No

---

When did you change to a flexible work schedule? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

Did you ever change to a less demanding job?

- ☐ Yes  
☐ No

---

When did you change to a less demanding job? Mark all that apply

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

How long did you stay in the less demanding job?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes  
☐ No

---

Did you make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

---

Please describe

---

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did you ever decide not to pursue an advancement or promotion?

- ☐ Yes  
☐ No

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did you retire earlier than you had planned?

- ☐ Yes  
☐ No

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did you delay retirement beyond when you had planned?

- ☐ Yes  
☐ No

**Other Aspects of Work**

**Please continue to think about all your work experiences from the time you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any physical tasks required by your job?

- ☐ Yes  
☐ No  
☐ I was never required to perform physical task as part of my job

Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks required by your job?

- ☐ Yes  
☐ No

Did you ever feel that, because of your cancer, its treatment, or the lasting effects of that treatment, you were less productive at work?

- ☐ Yes  
☐ No

Did you ever worry that, because of the effects of cancer on your health, you might be forced to retire or quit work before you are ready?

- ☐ Yes  
☐ No

Did you ever stay at a job in part because you were concerned about losing your health insurance?

- ☐ Yes  
☐ No

Were you concerned about losing your health insurance because of your cancer?

- ☐ Yes  
☐ No

Thinking about your work life or career, what effect has your experience with cancer, its treatment, or the lasting effects of that treatment had on it?

- ☐ Mostly positive effect  
☐ Mostly negative effect  
☐ Equally positive and negative effect  
☐ Neither positive nor negative effect

---

Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?

- ☐ Yes  
☐ No  
☐ Doesn't apply

---

### Caregivers

Since the time you were first diagnosed with cancer, has any friend or family member provided care to you during or after your cancer treatment?

- ☐ Yes  
☐ No

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties or employment status?

- ☐ Yes  
☐ No  
☐ None of my caregivers were employed while caring for me  
☐ I don't know

---

Did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties, or employment status for at least 2 months?

- ☐ Yes  
☐ No

---

Did any of your caregivers take extended paid time off from work (vacation and/or sick time)?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver took extended paid time off from work?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this caregiver's extended paid time off from work ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers take unpaid time off from work?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver took unpaid time off from work?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this caregiver's unpaid time off ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers change from working part-time to working full-time?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver worked full-time?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers' change from working full-time to working part time?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver worked part-time?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No  
☐ I don't know

---

Please specify

---

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers change to a less demanding job?

- ☐ Yes  
☐ No  
☐ I don't know

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers retire early?

- ☐ Yes  
☐ No  
☐ I don't know

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers delay retirement?

- ☐ Yes  
☐ No  
☐ I don't know

---

### Experiences with Health Insurance

**The next few questions are about health insurance coverage from the time you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

At any time from when you were first diagnosed with cancer to now, were you covered by health insurance that paid for all or part of your medical care, tests or cancer treatment?

- ☐ Yes  
☐ No  
☐ I don't know

---

Was there ever a time when health insurance refused to cover a visit for your cancer to the doctor or facility of your choice?

- ☐ Yes  
☐ No  
☐ Doesn't apply

---

Was there ever a time when health insurance refused to cover a second opinion about your cancer?

- ☐ Yes  
☐ No  
☐ I never asked for second opinion

---

Were you ever denied health insurance coverage because of your cancer?

- ☐ Yes  
☐ No  
☐ I never applied for health insurance

## The Effects of Cancer and Treatment on Finances

**The next questions ask about different kinds of financial burden you or your family may have experienced because of your cancer, its treatment, or the lasting effects of that treatment.**

**Please continue to think about all the time from when you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

Have you or has anyone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

How much did you or your family borrow, or how much debt did you incur because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Less than \$10,000  
☐ \$10,000 to \$24,999  
☐ \$25,000 to \$49,999  
☐ \$50,000 to \$74,999  
☐ \$75,000 to \$99,999  
☐ \$100,000 or more

Did you or your family ever file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

Have you or your family had to make any other kinds of financial sacrifices because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

Please describe

Have you ever worried about having to pay large medical bills related to your cancer?

- ☐ Yes  
☐ No

---

Please think about medical care visits for cancer, its treatment, or the lasting effects of that treatment. Have you ever been unable to cover your share of the cost of those visits?

- ☐ Yes  
☐ No

---

### Medical Care for Cancer

**These next questions ask about certain experiences you may have had when receiving medical care for cancer from the time you were first diagnosed to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you the need for regular follow-up care and monitoring even after completing your treatment?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you late or long-term side effects of cancer treatment you may experience over time?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you your emotional or social needs related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you lifestyle or health recommendations such as diet, exercise, quitting smoking?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did you get all of the medical care, tests, or treatments that you or your doctor believed were necessary?

- ☐ Yes  
☐ No

DON'T ASK QUESTIONS FROM THE MATRIX BELOW

GO TO THE NEXT SECTION "The effects....."

**Complete this matrix only when the response is "No" to the previous question".**

**Which of these are reasons you did not get all of the medical care, tests, or treatments you or a doctor believed you needed? Mark yes or no for each item below.**

	Yes, a reason	No, not a reason
Couldn't afford care. . . . .	<input type="radio"/>	<input type="radio"/>
Insurance company wouldn't approve or pay for care . . . . .	<input type="radio"/>	<input type="radio"/>
.....		
Doctor did not accept your insurance. . .	<input type="radio"/>	<input type="radio"/>
Had problems getting to doctor's office.	<input type="radio"/>	<input type="radio"/>
Couldn't get time off from work. . . . .	<input type="radio"/>	<input type="radio"/>
.....		
Didn't know where to go to get care. .	<input type="radio"/>	<input type="radio"/>
Couldn't get child care/adult care. . .	<input type="radio"/>	<input type="radio"/>
Didn't have time, care/test/treatment took too long. .	<input type="radio"/>	<input type="radio"/>
Other reason. . . . .	<input type="radio"/>	<input type="radio"/>

Ask this question only when there are multiple "YES" responses in the matrix above"  
GO TO THE NEXT SECTION "The effects....."

Please answer only if there are multiple reasons (multiple "Yes", selected) in the matrix above.

Which one of these is the main reason that you did not get all of the medical care, tests, or treatments you or a doctor believed you needed?

- ☐ Couldn't afford care
- ☐ Insurance company wouldn't approve or pay for care
- ☐ Doctor didn't accept your insurance
- ☐ Had problems getting to the doctors' office
- ☐ Couldn't get time off from work
- ☐ Didn't know where to go to get care
- ☐ Couldn't get child care/adult care
- ☐ Didn't have time, care/test/treatment took too long
- ☐ Some other reason.

Please specify

\_\_\_\_\_

## The Effects of Cancer and Its Treatment on Life in General

**The last few questions in the survey ask about how your cancer, its treatment and the lasting effects of that treatment may have influenced certain parts of your life.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

Did your cancer, its treatment, or the lasting effects of that treatment ever limit the kind or amount of activities you do outside of work, such as shopping, child care, exercising, studying, work around the house, and so on?

- ☐ Yes  
☐ No

How long were you or have you been limited in the kind or amount of usual daily activities?

- ☐ Less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to less than 3 years  
☐ 3 years to less than 5 years  
☐ 5 years to less than 10 years  
☐ More than 10 years

Is this limitation ongoing?

- ☐ Yes  
☐ No

Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks as part of your usual daily activities?

- ☐ Yes  
☐ No

Have you ever asked for help getting to a doctor or other healthcare provider because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

Did you ever receive help getting to a doctor or other healthcare provider?

- ☐ Yes  
☐ No

Have you ever asked for help understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

Did you ever receive help understanding health insurance or medical bills?

- ☐ Yes  
☐ No

---

How often do you worry that your cancer may come back or get worse?

- ☐ Never  
☐ Rarely  
☐ Sometimes  
☐ Often  
☐ All the time

---

How often do you worry that if your cancer came back or got worse it might keep you from fulfilling responsibilities at home or at work?

- ☐ Never  
☐ Rarely  
☐ Sometimes  
☐ Often  
☐ All the time

---

In your own opinion, what do you think are the chances that your cancer will come back or get worse within the next 10 years?

- ☐ Very low  
☐ Fairly low  
☐ Moderate  
☐ Fairly high  
☐ Very high  
☐ I don't know

---

**Have any of the following been positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment?**

**Please mark yes or no for each item below.**

	Yes	No
It has made me a stronger person.	<input type="radio"/>	<input type="radio"/>
I can cope better with life's challenges.	<input type="radio"/>	<input type="radio"/>
It became a reason to make positive changes in my life.	<input type="radio"/>	<input type="radio"/>
It has made me have healthier habits.	<input type="radio"/>	<input type="radio"/>

---

Please tell us anything else about your experiences with cancer.

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Source:

Agency for Healthcare Research and Quality 5600 Fishers Lane Rockville, MD 20857 Telephone: (301) 427-1364.  
The Agency for Healthcare Research and Quality and, Centers for Disease Control and Prevention U.S. Department of Health and Human Services

# Comprehensive Score for Financial Toxicity (COST)

**Below is a list of statements that other people with your illness have said are important. Please select one answer choice to indicate your response as it applies to the past 7 days.**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My out-of-pocket medical expenses are more than I thought they would be.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about the financial problems I will have in the future as a result of my illness or treatment.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I have no choice about the amount of money I spend on care.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am frustrated that I cannot work or contribute as much as I usually do.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my current financial situation.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to meet my monthly expenses .....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel financially stressed.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about keeping my job and income, including work at home.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My cancer or treatment has reduced my satisfaction with my present financial situation.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel in control of my financial situation.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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# NCCN Distress Thermometer and Problems List for Patients

Instructions: Please select the number between 0-10 that best describes how much distress you have been experiencing in the past week including today.

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

Please indicate if any of the following has been a problem for you in the past week including today.

## Practical Problems

Housing ☐ Yes ☐ No

Insurance/financial ☐ Yes ☐ No

Transportation ☐ Yes ☐ No

Work/school ☐ Yes ☐ No

Treatment decisions ☐ Yes ☐ No

## Family Problems

Dealing with children ☐ Yes ☐ No

Dealing with partner ☐ Yes ☐ No

Family health issues ☐ Yes ☐ No

## Emotional Problems

Depression ☐ Yes ☐ No

Fears ☐ Yes ☐ No

Nervousness ☐ Yes ☐ No

Sadness ☐ Yes ☐ No

Worry ☐ Yes ☐ No

Loss of interest in usual activities ☐ Yes ☐ No

**Spiritual/religious concerns**

Spiritual/religious concerns ☐ Yes ☐ No

**Physical Problems**

Appearance ☐ Yes ☐ No

Bathing/dressing ☐ Yes ☐ No

Breathing ☐ Yes ☐ No

Changes in urination ☐ Yes ☐ No

Constipation ☐ Yes ☐ No

Diarrhea ☐ Yes ☐ No

Eating ☐ Yes ☐ No

Fatigue ☐ Yes ☐ No

Feeling Swollen ☐ Yes ☐ No

Fevers ☐ Yes ☐ No

Getting around ☐ Yes ☐ No

Indigestion ☐ Yes ☐ No

Memory/concentration ☐ Yes ☐ No

Mouth sores ☐ Yes ☐ No

Nausea ☐ Yes ☐ No

Nose dry/congested ☐ Yes ☐ No

Pain ☐ Yes ☐ No

Sexual ☐ Yes ☐ No

Skin dry/itchy ☐ Yes ☐ No

Sleep ☐ Yes ☐ No

Substance abuse ☐ Yes ☐ No

Tingling in hands/feet ☐ Yes ☐ No

Adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines)

# PHQ-9

**Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(select one number on each line)**

**How often during the past 2 weeks were you bothered by....**

	Not at all 0	Several days 1	More than half the days 2	Nearly every day 3
1. Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Trouble falling or staying asleep, or sleeping too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Feeling tired or having little energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Poor appetite or overeating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Trouble concentrating on things, such as reading the newspaper or watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Moving or speaking so slowly that other people could have noticed. Or the opposite--being so fidgety or restless that you have been moving around a lot more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Thoughts that you would be better off dead or of hurting yourself in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Score \_\_\_\_\_

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## Service Satisfaction Scale of Cancer Care for PT(SSS-PT)

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Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your overall experience during the last year with care or therapy that you have received related to your cancer therapy or its side effects. By "practitioner" we mean the one or more doctors, clinicians, etc., who have worked with you in your cancer- related care.

**What is your overall feeling about the . . .**

	Completely Satisfied	Very Satisfied	Somewhat Satisfied	Mixed	Somewhat Unsatisfied	Very Unsatisfied	Completely Unsatisfied
Effect of health care services in helping you deal with your cancer and maintain your well being?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Professional knowledge and competence of your main cancer practitioner(s)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability of your main cancer practitioner(s) to listen and respond to your concerns or problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal manner of the main cancer practitioner(s) seen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waiting time between asking to be seen or treated and the appointment given?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waiting time when you come for an appointment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of appointment times that fit your schedule?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effect of cancer treatment in preventing cancer progression or recurrence?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well your confidentiality and rights as an individual have been protected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of cancer care you have received?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of information on how to get the most out of the cancer care and related services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Explanations of specific procedures and treatment approaches used?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effect of services in helping relieve symptoms or reduce problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoroughness of the main cancer practitioner(s) you have seen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Helpfulness of the information  
provided about your cancer and  
its treatment?

☐☐☐☐☐☐☐☐

In an overall general sense, how  
satisfied are you with the cancer  
treatment you have received?

☐☐☐☐☐☐☐☐

## Income And Insurance

**The next questions are about health insurance and health benefits because those things may affect the kind of care and treatment you get for your prostate cancer, or your health and well being overall. We will NOT contact your insurance company or tell them any of your answers.**

Since our last interview, have you had any kind of health insurance or health benefits?

This includes: Medicare, Medicaid or other public assistance programs, military insurance or VA health benefits, private insurance (through a job or union, or that you paid for yourself), and any other kind of health insurance you might have.

- ☐ ALL of the time
- ☐ PART of the time
- ☐ NONE of the time
- ☐ I don't know

---

Do you have any kind of health insurance or health benefits now?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

Please specify, why didn't you have the insurance?

---

Since our last interview, have you had any of the government-sponsored health insurance plans?

- ☐ Yes
- ☐ No

---

Since our last interview, have you had any of the MILITARY or VA health insurance plans or benefits?

- ☐ Yes
- ☐ No

---

Since our last interview, did you have any OTHER kind of health insurance, besides Government-sponsored and MILITARY or VA health insurance?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If Yes, please tell us what kind?

---

**The next questions are about the health insurance or health benefits you have NOW. If you do NOT have health insurance or benefits now, think about the last health insurance plan you had.**

Since our last interview, about how much money have you paid out of your own pocket for your medical care? Include money for doctors, dentists, eye glasses, hearing aides, and medicine.

- ☐ Less than \$500
- ☐ \$500 - \$999
- ☐ \$1,000 - \$1,999
- ☐ \$2,000 - \$2,999
- ☐ \$3,000 - \$4,999
- ☐ \$5,000 - \$6,999
- ☐ \$7,000 - \$9,999
- ☐ \$10,000 - \$11,999
- ☐ \$12,000 - \$13,999
- ☐ \$14,000 - \$15,999
- ☐ \$16,000 - \$17,999
- ☐ \$18,000 - \$19,999
- ☐ \$20,000 - \$24,999
- ☐ \$25,000 - \$29,999
- ☐ \$30,000 or more
- ☐ I don't know

Overall, how HAPPY or UNHAPPY are you with your health insurance or health benefits?  
Choose a number from 1 to 5, where 1 means your are Very UNHAPPY and 5 means you are Very HAPPY.

- ☐ 1 (Very Unhappy)
- ☐ 2
- ☐ 3 (Not Unhappy or Happy)
- ☐ 4
- ☐ 5 (Very Happy)

**The next questions are about your work and income. Your answers will help us understand how easy it is for you to get health care, and how prostate cancer has affected your life.**

Which of the following best describes what you do now?

- ☐ Full time paid work
- ☐ Part time paid work
- ☐ looking for work
- ☐ Unemployed now, but have a job to return to
- ☐ Unable to work because of PROSTATE CANCER or treatment
- ☐ Unable to work because of OTHER HEALTH PROBLEMS
- ☐ Retired because of disability or illness due to PROSTATE CANCER or treatment
- ☐ Retired because of disability or illness due to OTHER HEALTH PROBLEMS
- ☐ Retired because of age
- ☐ Retired by choice
- ☐ I don't know
- ☐ Other

Please specify

---

What is your current annual household income before you pay taxes? Count all kinds of income including: government benefits like Social Security, as well as work or farm income, and include your own income and any other person's income that goes toward your household expenses.

- ☐ Less than \$10,400 a year.... (or less than \$867 a month)
- ☐ \$10,401 - \$14,000 a year.... (or \$868 - \$1,167 a month)
- ☐ \$14,001 - \$17,600 a year.... (or \$1,168 - \$1,467 a month)
- ☐ \$17,601 - \$21,200 a year.... (or \$1,468 - \$1,767 a month)
- ☐ \$21,201 - \$24,800 a year.... (or \$1,768 - \$2,067 a month)
- ☐ \$24,801 - \$28,400 a year.... (or \$2,068 - \$2,367 a month)
- ☐ \$28,401 - \$32,000 a year.... (or \$2,368 - \$2,667 a month)
- ☐ \$32,001 - \$35,600 a year.... (or \$2,668 - \$2,967 a month)
- ☐ \$35,601 - \$39,200 a year.... (or \$2,968 - \$3,267 a month)
- ☐ \$39,201 - \$45,000 a year .... (or \$3,268 - \$3,750 a month)
- ☐ \$45,001 - \$50,000 a year.... (or \$3,751 - \$4,167 a month)
- ☐ \$50,001 - \$55,000 a year.... (or \$4,168 - \$4,583 a month)
- ☐ \$55,001 - \$60,000 a year.... (or \$4,584 - \$5,000 a month)
- ☐ \$60,001 - \$70,000 a year.... (or \$5,001 - 5,833 a month)
- ☐ \$70,001 - \$80,000 a year.... (or \$5,834 - \$6,667 a month)
- ☐ \$80,001 or more a year.... (or \$6,668 or more a month)
- ☐ I don't know

---

Including yourself, how many people are supported by this income?

- ☐ 1 person, I am the only person supported by this income
- ☐ 2 people
- ☐ 3 people
- ☐ 4 people
- ☐ 5 people
- ☐ 6 people
- ☐ 7 people
- ☐ 8 people
- ☐ 9 or more people
- ☐ I don't know

---

Sometimes people put off getting medical care that they need. Since our last interview, have you had to delay getting medical care?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If YES, did you put off getting medical care for any of the following reasons? Check ALL that apply.

- ☐ I couldn't get through on the telephone
- ☐ I couldn't get an appointment soon enough
- ☐ I would have to wait too long at the doctor's office
- ☐ The clinic or doctor's office wasn't open when I could get there
- ☐ I couldn't take time off from work to go
- ☐ I didn't have any way to get there
- ☐ I couldn't afford the cost of transportation to get there
- ☐ I couldn't afford the cost of the visit
- ☐ I couldn't afford the medicine or treatments
- ☐ I don't know
- ☐ Other

---

Please specify

\_\_\_\_\_

## Physical Health And Health Behavior

Since our last interview, who has given you emotional support? Check ALL that apply.

- ☐ Wife or Partner
- ☐ Daughter or Son
- ☐ Sister or Brother
- ☐ Mother or Father
- ☐ Other relative
- ☐ Friend(s)
- ☐ Neighbor(s)
- ☐ Co-worker(s)
- ☐ Church Member(s)
- ☐ Priest, or other religious advisor
- ☐ God
- ☐ Club member(s)
- ☐ Prostate cancer support group
- ☐ Your doctor or doctors
- ☐ A counselor or therapist
- ☐ No one
- ☐ I don't know
- ☐ Other

Please specify \_\_\_\_\_

In general, how many close friends do you have? A "close friend" would be anyone you feel at ease with, can talk to about private things, and can call on for help. This could include your wife or other relatives, as well as friends who are not relatives.

- ☐ No one
- ☐ 1-3
- ☐ 4 - 5
- ☐ 6 - 7
- ☐ 8 or more

### SMOKING AND DRINKING

Since our last interview, have you smoked cigarettes at least once a day at any time?

- ☐ Yes
- ☐ No
- ☐ I don't know

If YES, about how many cigarettes did you smoke on a normal day?

- ☐ 1 - 2
- ☐ 3 - 5
- ☐ 6 - 10
- ☐ 11 - 15
- ☐ 16 - 20
- ☐ 21 - 30 (1 - 1 1/2 packs a day)
- ☐ 31 - 40 (1 1/2 - 2 packs a day)
- ☐ More than 2 packs a day
- ☐ I don't know

If YES, do you smoke cigarettes at least once a day now?

- ☐ Yes
- ☐ No
- ☐ I don't know

Do you use any of the products listed below at least once a day now?

- ☐ Chewing tobacco
- ☐ Cigars
- ☐ Snuff
- ☐ Pipe

How often do you drink beer?

- ☐ NEVER
- ☐ Once a month or less
- ☐ 2 - 3 times a month
- ☐ 1 - 2 times a week
- ☐ 3 - 4 times a week
- ☐ 5 - 6 times a week
- ☐ Every day

If you drink beer, how much do you usually drink?

- ☐ Less than 1 can or bottle (12 oz.)
- ☐ 1 - 2 cans or bottles
- ☐ 3 or more cans or bottles

How often do you drink wine or wine coolers?

- ☐ NEVER
- ☐ Once a month or less
- ☐ 2 - 3 times a month
- ☐ 1 - 2 times a week
- ☐ 3 - 4 times a week
- ☐ 5 - 6 times a week
- ☐ Every day

If you drink wine or wine coolers, how much do you usually drink?

- ☐ Less than 1 glass
- ☐ 1 - 2 glasses
- ☐ More than 2 glasses

How often do you drink liquor?

- ☐ NEVER
- ☐ Once a month or less
- ☐ 2 - 3 times a month
- ☐ 1 - 2 times a week
- ☐ 3 - 4 times a week
- ☐ 5 - 6 times a week
- ☐ Every day

If you drink liquor or mixed drinks, how much do you usually drink?

- ☐ Less than 1 shot of liquor
- ☐ 1 - 3 shots of liquor
- ☐ More than 3 shots of liquor

**The next questions are about your USUAL EXERCISE and PHYSICAL ACTIVITY. Please do NOT include work you did as part of your job.**

In the past 12 months, did you do any LIGHT exercise that didn't make you breathe any harder than usual at least once a week?

NOTE: "Light exercise" includes things like light yard work (gardening or pruning), light house work (dusting or vacuuming), playing golf with a cart, very easy bicycling or swimming, or light stretching.

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If YES, how many days a week did you do any kind of LIGHT exercise?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days
- 

If YES, how many hours a day did you do any kind of LIGHT exercise?

- ☐ Less than 1 hour  
☐ 1 - 2 hours  
☐ 3 hours or more
- 

In the past 12 months, did you do MODERATE exercise that made you breathe somewhat harder than usual, at least once a week?

NOTE: "Moderate exercise" includes things like brisk walking or running, golfing without a cart or caddy, recreational swimming, moderate yard work (mowing with a power mower), doubles tennis, ballroom dancing, low impact or water aerobics, moderate housework (scrubbing floors or washing windows), or slow bicycling on level ground.

- ☐ Yes  
☐ No  
☐ I don't know
- 

If YES, how many days a week did you do any kind of MODERATE exercise?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days
- 

If YES, how many minutes a day did you do any kind of MODERATE exercise?

- ☐ 10 - 25 minutes  
☐ 30 - 40 minutes  
☐ 45 - 55 minutes  
☐ 60 minutes or more
- 

In the past 12 months, did you do VIGOROUS exercise that made you breathe much harder than usual, at least once a week?

NOTE: "Vigorous exercise" includes things like race-walking, jogging or running, aerobics, swimming laps, using a push mower, singles tennis, racquetball or squash, fast or steep hill bicycling, heavy housework, circuit training, stair machine, clogging or line dancing.

- ☐ Yes  
☐ No  
☐ I don't know
- 

If YES, how many days a week did you do any kind of VIGOROUS exercise?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days

---

If YES, how many minutes a day did you do any kind of VIGOROUS exercise?

- ☐ 10 - 25 minutes
- ☐ 30 - 40 minutes
- ☐ 45 - 55 minutes
- ☐ 60 minutes or more

---

**FINAL QUESTION**

---

Do you have any other comments or suggestions?

---

"The PHQ-9 in the survey you have completed screens for depression, but please advise that this is not a diagnosis of your current mental health status. Please visit the National Alliance on Mental Illness website (<https://www.nami.org>) for more information on resources and services available or call the Suicide Prevention Lifeline at 1-800-273-8255 if you need immediate support."

# PCaP Follow-up Contact Info

Thank you for taking part in the North Carolina-Louisiana Prostate Cancer Project (PCaP).

Please complete the survey below.

Thank you,

---

Today's Date

---

---

Please enter the year when you had last interview with PCaP?

---

---

First name

---

---

Last name

---

---

Full Name

---

---

What race do you consider yourself to be?

- ☐ White  
☐ Black  
☐ Other

---

Please specify your race?

---

**Please provide us your address below**

Address

---

City

---

State

---

Zipcode

---

Please enter your cell phone number

---

Please enter your work phone number

---

Please enter your home phone number

---

# Demographics

Please complete the survey below.

Thank you!

**Do you have a friend or relative who could help us get in touch with you if we have trouble reaching you in the future? If so, please write their name and other information below.**

First name

---

Last name

---

Home phone number

---

Cell or mobile phone number

---

Work phone number

---

Email

---

Can you please tell me your date of birth?

---

What is your current marital status?

- ☐ Married or Living as Married
- ☐ Widowed
- ☐ Separated
- ☐ Divorced
- ☐ Never married

Has your marital status changed since you were diagnosed with prostate cancer?

- ☐ Yes
- ☐ No

Since our last interview, have you moved?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If yes, why did you move? Check ALL that apply.

- ☐ To live in a new or better house or location
- ☐ To be closer to my doctor or clinic
- ☐ To be closer to my family
- ☐ To be closer to my friends
- ☐ So I could get help with daily activities
- ☐ So I could get help with medical care
- ☐ So my wife or partner could get help with daily activities
- ☐ So my wife or partner could get medical care
- ☐ To cut costs
- ☐ Because I could not afford to pay my rent, mortgage, property taxes or other expenses
- ☐ I don't know
- ☐ Other

---

Please specify

\_\_\_\_\_

---

Which of the following best describes where you live now?

- ☐ Your own home or apartment
- ☐ A relative's home or apartment
- ☐ A friend's home or apartment
- ☐ A continuing care facility where you are living independently
- ☐ A nursing home or other group facility where you get daily care and assistance
- ☐ A shelter
- ☐ A hospice
- ☐ Some other living arrangement
- ☐ I don't have a regular living place

---

Do you own or partly own the place where you live?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

How many other people live with you?

- ☐ I live alone
- ☐ 1
- ☐ 2
- ☐ 3 - 4
- ☐ 5 - 6
- ☐ 7 - 10
- ☐ More than 10
- ☐ I don't know

---

If you live with other people, what relation are they to you?

- ☐ Wife or Partner
- ☐ One or more dependent children
- ☐ One or more adult children
- ☐ Other relatives
- ☐ Friend(s)
- ☐ Paid caregiver(s)
- ☐ Other
- ☐ I don't know

**We would like to ask who has helped you with your care most?**

Name

---

Relationship

---

Address

---

City

---

State	<input type="radio"/> Alabama <input type="radio"/> Alaska <input type="radio"/> Arizona <input type="radio"/> Arkansas <input type="radio"/> California <input type="radio"/> Colorado <input type="radio"/> Connecticut <input type="radio"/> Delaware <input type="radio"/> Florida <input type="radio"/> Georgia <input type="radio"/> Hawaii <input type="radio"/> Idaho <input type="radio"/> Illinois <input type="radio"/> Indiana <input type="radio"/> Iowa <input type="radio"/> Kansas <input type="radio"/> Kentucky <input type="radio"/> Louisiana <input type="radio"/> Maine <input type="radio"/> Maryland <input type="radio"/> Massachusetts <input type="radio"/> Michigan <input type="radio"/> Minnesota <input type="radio"/> Mississippi <input type="radio"/> Missouri <input type="radio"/> Montana <input type="radio"/> Nebraska <input type="radio"/> Nevada <input type="radio"/> New Hampshire <input type="radio"/> New Jersey <input type="radio"/> New Mexico <input type="radio"/> New York <input type="radio"/> North Carolina <input type="radio"/> North Dakota <input type="radio"/> Ohio <input type="radio"/> Oklahoma <input type="radio"/> Oregon <input type="radio"/> Pennsylvania <input type="radio"/> Rhode Island <input type="radio"/> South Carolina <input type="radio"/> South Dakota <input type="radio"/> Tennessee <input type="radio"/> Texas <input type="radio"/> Utah <input type="radio"/> Vermont <input type="radio"/> Virginia <input type="radio"/> Washington <input type="radio"/> West Virginia <input type="radio"/> Wisconsin <input type="radio"/> Wyoming
Zip	<input type="text"/>
Email	<input type="text"/>
Home Phone	<input type="text"/>
Cell Phone	<input type="text"/>

---

How long have you known [caregiver\_1]?  
(In years)

\_\_\_\_\_

(years)

---

On average, how many hours in a day does  
[caregiver\_1] spend taking care of you?

\_\_\_\_\_

(hours)

---

How long has [caregiver\_1] been your care giver?

\_\_\_\_\_

(years)

---

Did anyone else help you with your cancer care?

☐ Yes  
☐ No

---

Name

\_\_\_\_\_

---

Relationship

\_\_\_\_\_

---

Please select all types of care you get from your caregiver

- ☐ Help with activities of daily living such as: get in and out of beds, get dressed, get to and from the toilet.....
- ☐ Help with instrumental of activities of daily living such as: transportation, housework, grocery or other shopping, preparing meals, managing finances....
- ☐ Help with communicating with healthcare professionals, monitoring severity, and advocating.

# SF 12 Version2 Health Survey

Please complete the survey below.

Thank you!

**INSTRUCTIONS: Now, the following question ask for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.**

In general, would you say your health is:

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

**The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, not limited at all

Climbing several flights of stairs

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, Not limited at all

**During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

Accomplished less than you would like

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Were limited in the kind of work or other activities

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

Accomplished less than you would like

- ☐ All of the time  
☐ Most of the time  
☐ Some of the time  
☐ A little of the time  
☐ None of the time

Were limited in the kind of work or other activities

- ☐ All of the time  
☐ Most of the time  
☐ Some of the time  
☐ A little of the time  
☐ None of the time

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all  
☐ A little bit  
☐ Moderately  
☐ Quite a bit  
☐ Extremely

**These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

**How much of the time during the past 4 weeks...**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Charlson Comorbidity Index (CCI)

Please complete the survey below.

Thank you!

**Below is the list of some health condition, please mark the check box if you have been diagnosed with any of these conditions.**

Comorbidity (Choose all that are present)

- ☐ Myocardial infarct (+1)
- ☐ Congestive heart failure (+1)
- ☐ Peripheral vascular disease (+1)
- ☐ Cerebrovascular disease (except hemiplegia) (+1)
- ☐ Dementia (+1)
- ☐ Chronic pulmonary disease (+1)
- ☐ Connective tissue disease (+1)
- ☐ Ulcer disease (+1)
- ☐ Mild liver disease (+1)
- ☐ Diabetes (without complications) (+1)
- ☐ Diabetes with end organ damage (+2)
- ☐ Hemiplegia (+2)
- ☐ Moderate or severe renal disease (+2)
- ☐ Solid tumor (non metastatic) (+2)
- ☐ Leukemia (+2)
- ☐ Lymphoma, Multiple myeloma (+2)
- ☐ Moderate or severe liver disease (+3)
- ☐ Metastatic solid tumor (+6)
- ☐ AIDS (+6)

Do you have any other health problem?

- ☐ Yes
- ☐ No

If yes, please specify

Charlson ME, Pompei P, Ales KL, MacKenzie CR, A new method of classifying prognostic comorbidity in longitudinal studies: development and validation, 373-383, (c) Elsevier (1987)  
Journal of Diseases Homepage <http://www.sciencedirect.com/science/journal/00219681> Additional information:  
SCORING-<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC545968/>

# Medical

Please complete the survey below.

Thank you!

## PSA

How long has it been since your last PSA test?

- ☐ Less than 1 month
- ☐ 1 - 2 months
- ☐ 3 - 4 months
- ☐ 5 - 6 months
- ☐ 7 - 8 months
- ☐ 9 - 10 months
- ☐ 11 - 12 months
- ☐ 1 - 1-1/2 years
- ☐ 1-1/2 - 2 years
- ☐ More than 2 years
- ☐ I don't know

Do you know if your PSA level was undetectable last time you were tested?

- ☐ Yes
- ☐ No
- ☐ I don't know

Do you remember the name of your doctor who did your last PSA test?

- ☐ Yes
- ☐ No

Name of Doctor

---

Do you remember the name of HOSPITAL where you had PSA test?

- ☐ Yes
- ☐ No

Name of hospital/clinic or lab

---

Do you remember the address of hospital where you had PSA test?

- ☐ Yes
- ☐ No

Street

---

City

---

State

---

Zip

---

---

Since our last interview, have you been followed up regarding prostate cancer?

- ☐ Yes  
☐ No  
☐ I don't know

---

Can you please tell us the doctor's name?

---

---

Hospital/Clinic Name

---

---

Street

---

---

City

---

---

State

---

---

Zip Code

---

---

What kinds of doctors or health care professionals have you talked to about your prostate cancer or treatment?  
Check ALL that apply.

- ☐ A urologist  
☐ A radiation oncologist  
☐ A medical oncologist  
☐ I don't know  
☐ Other

---

Please specify

---

---

**Please tell us who are seeing for your primary health care.**

Name of Doctor

---

---

Name of clinic

---

---

Address of the clinic

---

---

City of clinic

---

---

State

---

---

Zip

---

---

Is this person monitoring your PSA?

☐ Yes

☐ No

---

Since our last interview, have you had any of the following procedures or tests? Check ALL that apply.

☐ A trans-rectal ultrasound examination of your prostate

☐ MRI

☐ CT scan

☐ Bone scan

☐ I don't know

☐ None

---

Since our last interview, have you participated in any clinical trials to test new prostate cancer treatments?

☐ Yes, one clinical trial

☐ Yes, more than one clinical trial

☐ No

☐ I don't know

---

## DRE

How long has it been since your last Digital Rectal Exam (DRE)?

☐ Less than 1 month

☐ 1 - 2 months

☐ 3 - 4 months

☐ 5 - 6 months

☐ 7 - 8 months

☐ 9 - 10 months

☐ 11 - 12 months

☐ 1 - 1-1/2 years

☐ 1-1/2 - 2 years

☐ More than 2 years

☐ I don't know

---

Since our last interview, have you had a follow-up biopsy of your prostate taken with a needle through your rectum?

☐ Yes

☐ No

☐ I don't know

---

How long has it been since your last follow-up biopsy?

☐ Less than 1 month

☐ 1 - 2 months

☐ 3 - 4 months

☐ 5 - 6 months

☐ 7 - 8 months

☐ 9 - 10 months

☐ 11 - 12 months

☐ 1 - 1-1/2 years

☐ 1-1/2 - 2 years

☐ More than 2 years

☐ I don't know

Since our last interview, did you have to make a NEW decision about what to do about your prostate cancer? (This could be deciding whether to have a new kind of treatment, whether to keep having or stop treatment you were already having, etc.)

- ☐ Yes  
☐ No  
☐ I don't know

Since our last interview, between you and your doctor, who was mostly responsible for deciding what to do about your prostate cancer?

- ☐ I was mostly responsible for deciding what to do  
☐ My doctor and I were both responsible  
☐ My doctor was mostly responsible for deciding what to do  
☐ I don't know

**Since our last interview, how much do you agree or disagree with the following statements about the NEW treatment decisions you made? Please choose a number from 1 to 5, where 1 means you Strongly DISAGREE and 5 means you Strongly AGREE with the statement.**

	1 (Strongly Disagree)	2	3 ( Don't Agree or Disagree)	4	5 (Strongly Agree)
I had all the information I needed to make a decision about treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My doctors told me the whole story about side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew the right questions to ask the doctor about treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had enough time to make a decision about treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the treatment choices I made.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**The next questions are about your health and the quality of your life as a prostate cancer survivor. We know that many of these questions are personal, but your answers are important to help us understand why life is better for some men with prostate cancer than it is for others.**

Since our last interview, have you had any problems with urination?

- ☐ Yes  
☐ No  
☐ I don't know

If YES, have you had any of the problems listed below? Check ALL that apply.

- ☐ Difficulty passing urine  
☐ Frequent or urgent urination  
☐ Problems with leaking urine (incontinence)  
☐ Pain during urination  
☐ Blood in urine  
☐ I don't know  
☐ Other

---

Please specify

---

---

Have you talked to a doctor about problems with urination since our last interview?

- ☐ Yes  
☐ No  
☐ I don't know
- 

Since our last interview, have you had any problems with erections or your sexual function?

- ☐ Yes  
☐ No  
☐ I don't know

# EPIC-26

Please complete the survey below.

Thank you!

## EPIC-26

**The Expanded Prostate Cancer Index Composite Short Form** This questionnaire is designed to measure Quality of Life issues in patients with Prostate cancer. To help us get the most accurate measurement, it is important that you answer all questions honestly and completely. Remember, as with all medical records, information contained within this survey will remain strictly confidential.

Over the past 4 weeks, how often have you leaked urine?

- ☐ More than once a day
- ☐ About once a day
- ☐ More than once a week
- ☐ About once a week
- ☐ Rarely or never

Which of the following best describes your urinary control during the last 4 weeks?

- ☐ No urinary control whatsoever
- ☐ Frequent dribbling
- ☐ Occasional dribbling
- ☐ Total control

How many pads or adult diapers per day did you use to control leakage during the last 4 weeks?

- ☐ None
- ☐ 1 per day
- ☐ 2 per day
- ☐ 3 or more per day

## How big a problem, if any, has each of the following been for you during the last 4 weeks?

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
Dripping or leaking urine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain or burning on urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bleeding with urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weak urine stream or incomplete emptying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Need to urinate frequently during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall, how big a problem has your urinary function been for you during the last 4 weeks?

- ☐ No problem  
☐ Very small problem  
☐ Small problem  
☐ Moderate problem  
☐ Big problem

**How big a problem, if any, has each of the following been for you?**

	No Problem	Very Small Problem	Small Problem	Moderate Problem	Big Problem
Urgency to have a bowel movement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Increased frequency of bowel movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control of your stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bloody stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abdominal/Pelvic/Rectal pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall, how big a problem have your bowel habits been for you during the last 4 weeks?

- ☐ No problem  
☐ Very small problem  
☐ Small problem  
☐ Moderate problem  
☐ Big problem

**How would you rate each of the following during the last 4 weeks?**

	Very poor to none	Poor	Fair	Good	Very good
Your ability to have an erection?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your ability to reach orgasm (climax)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How would you describe the usual QUALITY of your erections during the last 4 weeks?

- ☐ None at all  
☐ Not firm enough for any sexual activity  
☐ Firm enough for masturbation and foreplay only  
☐ Firm enough for intercourse

How would you describe the FREQUENCY of your erections during the last 4 weeks?

- ☐ I NEVER had an erection when I wanted one  
☐ I had an erection LESS THAN HALF the time I wanted one  
☐ I had an erection ABOUT HALF the time I wanted one  
☐ I had an erection MORE THAN HALF the time I wanted one  
☐ I had an erection WHENEVER I wanted one

---

Overall, how would you rate your ability to function sexually during the last 4 weeks?

- ☐ Very poor  
☐ Poor  
☐ Fair  
☐ Good  
☐ Very good

---

Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?

- ☐ No problem  
☐ Very small problem  
☐ Small problem  
☐ Moderate problem  
☐ Big problem

---

**How big a problem during the last 4 weeks, if any, has each of the following been for you?**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
Hot flashes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breast tenderness/enlargement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change in body weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

Urinary Incontinence

---

---

Urinary Obstructive/Irritative

---

---

Bowel

---

---

Sexual

---

---

Hormonal

---

---

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Wei J, Dunn R, Litwin M, Sandler H, and Sanda M. "Development and Validation of the Expanded Prostate Cancer Index Composite (EPIC) for Comprehensive Assessment of Health-Related Quality of Life in Men with Prostate Cancer", Urology. 56: 899-905, 2000.

# Medical Expenditure Panel Survey (MEPS)

Please complete the survey below.

Thank you!

## Cancer History

Are you currently being treated for cancer - that is are you planning or recovering from cancer surgery, or receiving chemotherapy, radiation therapy, or hormonal therapy for your cancer?

☐ Yes ☐ No

To the best of your knowledge, are you now free of cancer?

☐ Yes ☐ No ☐ I don't know

About how long ago did you receive your last cancer treatment?

- ☐ Less than 1 year ago  
☐ 1 year ago to less than 3 years ago  
☐ 3 years ago to less than 5 years ago  
☐ 5 years ago to less than 10 years ago  
☐ 10 years ago to 20 years ago  
☐ More than 20 years ago  
☐ I have not been treated for cancer

Did a doctor or other health professional ever tell you that your cancer had come back?

☐ Yes ☐ No

What was the most recent year a doctor or health professional told you that your cancer had come back? \_\_\_\_\_

Is this the first time you have been treated for any type of cancer?

☐ Yes  
☐ No

## Changes to Your Work Schedule

At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business?

☐ Yes ☐ No

**These next questions ask about different ways cancer, its treatment, or the lasting effects of that treatment may have affected your work - that is, your hours, duties, or employment status.**

**As you answer these questions, please think about the entire time from when you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

At any time since your first cancer diagnosis, did you take extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

☐ Yes ☐ No

At any time since your first cancer diagnosis, did you ask for extended paid time off from work, unpaid time off, or a change in your hours, duties or employment status?

☐ Yes ☐ No

Did you ask for these work changes...

- ☐ Because of your cancer, its treatment or its lasting effects?  
☐ Some other reason

Did you ever take extended paid time off from work (vacation, sick time and/or disability leave)? By extended time off, we mean more than an occasional day off here and there.

☐ Yes  
☐ No

When did you take extended paid time off from work? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

What do you estimate was the total amount of extended paid time off from work that you took?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

Is your extended paid time off from work ongoing?

☐ Yes ☐ No

Did you ever take unpaid time off from work?

☐ Yes ☐ No

---

When did you take unpaid time off from work? Mark all that apply.

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

---

What do you estimate was the total amount of unpaid time off from work that you took?

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

---

Is your unpaid time off ongoing?

- ☐ Yes
- ☐ No

---

Did you ever change from working part-time to working full-time?

- ☐ Yes
- ☐ No

---

When did you change from working part-time to working full-time? Mark all that apply.

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

---

What do you estimate was the total amount of time you worked full-time?

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes
- ☐ No

---

Did you ever change from working full time to working part-time?

- ☐ Yes
- ☐ No

---

When did you change from working full-time to working part-time? Mark all that apply.

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

---

What do you estimate was the total amount of time you worked part-time?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes ☐ No

---

Did you ever change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day-to-day?

- ☐ Yes  
☐ No

---

When did you change to a flexible work schedule? Mark all that apply.

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

Did you ever change to a less demanding job?

- ☐ Yes  
☐ No

---

When did you change to a less demanding job? Mark all that apply

- ☐ At the time of diagnosis  
☐ During treatment  
☐ Less than one year after treatment was finished  
☐ One year or more after treatment was finished

---

How long did you stay in the less demanding job?

- ☐ Less than 2 months  
☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes  
☐ No

---

Did you make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

---

Please describe

---

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did you ever decide not to pursue an advancement or promotion?

- ☐ Yes  
☐ No

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did you retire earlier than you had planned?

- ☐ Yes  
☐ No

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did you delay retirement beyond when you had planned?

- ☐ Yes  
☐ No

---

### Other Aspects of Work

**Please continue to think about all your work experiences from the time you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any physical tasks required by your job?

- ☐ Yes  
☐ No  
☐ I was never required to perform physical task as part of my job

---

Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks required by your job?

- ☐ Yes  
☐ No

---

Did you ever feel that, because of your cancer, its treatment, or the lasting effects of that treatment, you were less productive at work?

- ☐ Yes  
☐ No

---

Did you ever worry that, because of the effects of cancer on your health, you might be forced to retire or quit work before you are ready?

- ☐ Yes  
☐ No

---

Did you ever stay at a job in part because you were concerned about losing your health insurance?

- ☐ Yes  
☐ No

---

Were you concerned about losing your health insurance because of your cancer?

- ☐ Yes  
☐ No

---

Thinking about your work life or career, what effect has your experience with cancer, its treatment, or the lasting effects of that treatment had on it?

- ☐ Mostly positive effect  
☐ Mostly negative effect  
☐ Equally positive and negative effect  
☐ Neither positive nor negative effect

---

Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?

- ☐ Yes  
☐ No  
☐ Doesn't apply

---

### Caregivers

Since the time you were first diagnosed with cancer, has any friend or family member provided care to you during or after your cancer treatment?

- ☐ Yes  
☐ No

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties or employment status?

- ☐ Yes  
☐ No  
☐ None of my caregivers were employed while caring for me  
☐ I don't know

---

Did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties, or employment status for at least 2 months?

- ☐ Yes  
☐ No

---

Did any of your caregivers take extended paid time off from work (vacation and/or sick time)?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver took extended paid time off from work?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this caregiver's extended paid time off from work ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers take unpaid time off from work?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver took unpaid time off from work?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this caregiver's unpaid time off ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers change from working part-time to working full-time?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver worked full-time?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers' change from working full-time to working part time?

- ☐ Yes  
☐ No

---

How long do you estimate this caregiver worked part-time?

- ☐ 2 months to less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to 3 years  
☐ More than 3 years

---

Is this change ongoing?

- ☐ Yes  
☐ No

---

Did any of your caregivers make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No  
☐ I don't know

---

Please specify

---

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers change to a less demanding job?

- ☐ Yes  
☐ No  
☐ I don't know

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers retire early?

- ☐ Yes  
☐ No  
☐ I don't know

---

Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers delay retirement?

- ☐ Yes  
☐ No  
☐ I don't know

---

### Experiences with Health Insurance

**The next few questions are about health insurance coverage from the time you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

At any time from when you were first diagnosed with cancer to now, were you covered by health insurance that paid for all or part of your medical care, tests or cancer treatment?

- ☐ Yes  
☐ No  
☐ I don't know

---

Was there ever a time when health insurance refused to cover a visit for your cancer to the doctor or facility of your choice?

- ☐ Yes  
☐ No  
☐ Doesn't apply

---

Was there ever a time when health insurance refused to cover a second opinion about your cancer?

- ☐ Yes  
☐ No  
☐ I never asked for second opinion

---

Were you ever denied health insurance coverage because of your cancer?

- ☐ Yes  
☐ No  
☐ I never applied for health insurance

---

### The Effects of Cancer and Treatment on Finances

**The next questions ask about different kinds of financial burden you or your family may have experienced because of your cancer, its treatment, or the lasting effects of that treatment.**

**Please continue to think about all the time from when you were first diagnosed with cancer to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

Have you or has anyone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

---

How much did you or your family borrow, or how much debt did you incur because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Less than \$10,000  
☐ \$10,000 to \$24,999  
☐ \$25,000 to \$49,999  
☐ \$50,000 to \$74,999  
☐ \$75,000 to \$99,999  
☐ \$100,000 or more

---

Did you or your family ever file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

---

Have you or your family had to make any other kinds of financial sacrifices because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

---

Please describe

---

Have you ever worried about having to pay large medical bills related to your cancer?

- ☐ Yes  
☐ No

---

Please think about medical care visits for cancer, its treatment, or the lasting effects of that treatment. Have you ever been unable to cover your share of the cost of those visits?

- ☐ Yes  
☐ No

---

### Medical Care for Cancer

**These next questions ask about certain experiences you may have had when receiving medical care for cancer from the time you were first diagnosed to now.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you the need for regular follow-up care and monitoring even after completing your treatment?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you late or long-term side effects of cancer treatment you may experience over time?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you your emotional or social needs related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

---

At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you lifestyle or health recommendations such as diet, exercise, quitting smoking?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

At any time since you were first diagnosed with cancer, did you get all of the medical care, tests, or treatments that you or your doctor believed were necessary?

- ☐ Yes  
☐ No

PLEASE SKIP THE MATRIX BELOW

GO TO THE NEXT SECTION "The effects....."

**Complete this matrix only when the response is "No" to the previous question".**

**Which of these are reasons you did not get all of the medical care, tests, or treatments you or a doctor believed you needed? Mark yes or no for each item below.**

	Yes, a reason	No, not a reason
Couldn't afford care. . . . .	<input type="radio"/>	<input type="radio"/>
Insurance company wouldn't approve or pay for care . . . . .	<input type="radio"/>	<input type="radio"/>
Doctor did not accept your insurance. . .	<input type="radio"/>	<input type="radio"/>
Had problems getting to doctor's office.	<input type="radio"/>	<input type="radio"/>
Couldn't get time off from work. . .	<input type="radio"/>	<input type="radio"/>
Didn't know where to go to get care. .	<input type="radio"/>	<input type="radio"/>
Couldn't get child care/adult care. . .	<input type="radio"/>	<input type="radio"/>
Didn't have time, care/test/treatment took too long. .	<input type="radio"/>	<input type="radio"/>
Other reason. . . . .	<input type="radio"/>	<input type="radio"/>

Please answer only if there are multiple reasons (multiple "Yes", selected) in the matrix above.  
 If not, GO TO THE NEXT SECTION "The effects....."

Which one of these is the main reason that you did not get all of the medical care, tests, or treatments you or a doctor believed you needed?

- ☐ Couldn't afford care  
☐ Insurance company wouldn't approve or pay for care  
☐ Doctor didn't accept your insurance  
☐ Had problems getting to the doctors' office  
☐ Couldn't get time off from work  
☐ Didn't know where to go to get care  
☐ Couldn't get child care/adult care  
☐ Didn't have time, care/test/treatment took too long  
☐ Some other reason.

Please specify

## The Effects of Cancer and Its Treatment on Life in General

**The last few questions in the survey ask about how your cancer, its treatment and the lasting effects of that treatment may have influenced certain parts of your life.**

**If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

Did your cancer, its treatment, or the lasting effects of that treatment ever limit the kind or amount of activities you do outside of work, such as shopping, child care, exercising, studying, work around the house, and so on?

- ☐ Yes  
☐ No

How long were you or have you been limited in the kind or amount of usual daily activities?

- ☐ Less than 6 months  
☐ 6 months to less than 1 year  
☐ 1 year to less than 3 years  
☐ 3 years to less than 5 years  
☐ 5 years to less than 10 years  
☐ More than 10 years

Is this limitation ongoing?

- ☐ Yes  
☐ No

Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks as part of your usual daily activities?

- ☐ Yes  
☐ No

Have you ever asked for help getting to a doctor or other healthcare provider because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

Did you ever receive help getting to a doctor or other healthcare provider?

- ☐ Yes  
☐ No

Have you ever asked for help understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes  
☐ No

Did you ever receive help understanding health insurance or medical bills?

- ☐ Yes  
☐ No

---

How often do you worry that your cancer may come back or get worse?

- ☐ Never  
☐ Rarely  
☐ Sometimes  
☐ Often  
☐ All the time

---

How often do you worry that if your cancer came back or got worse it might keep you from fulfilling responsibilities at home or at work?

- ☐ Never  
☐ Rarely  
☐ Sometimes  
☐ Often  
☐ All the time

---

In your own opinion, what do you think are the chances that your cancer will come back or get worse within the next 10 years?

- ☐ Very low  
☐ Fairly low  
☐ Moderate  
☐ Fairly high  
☐ Very high  
☐ I don't know

---

**Have any of the following been positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment?**

**Please mark yes or no for each item below.**

	Yes	No
It has made me a stronger person.	<input type="radio"/>	<input type="radio"/>
I can cope better with life's challenges.	<input type="radio"/>	<input type="radio"/>
It became a reason to make positive changes in my life.	<input type="radio"/>	<input type="radio"/>
It has made me have healthier habits.	<input type="radio"/>	<input type="radio"/>

---

Please tell us anything else about your experiences with cancer.

---

Source:

Agency for Healthcare Research and Quality 5600 Fishers Lane Rockville, MD 20857 Telephone: (301) 427-1364.  
The Agency for Healthcare Research and Quality and, Centers for Disease Control and Prevention U.S. Department of Health and Human Services

# Comprehensive Score for Financial Toxicity (COST)

Please complete the survey below.

Thank you!

**Below is a list of statements that other people with your illness have said are important. Please select one answer choice to indicate your response as it applies to the past 7 days.**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My out-of-pocket medical expenses are more than I thought they would be.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about the financial problems I will have in the future as a result of my illness or treatment.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I have no choice about the amount of money I spend on care.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am frustrated that I cannot work or contribute as much as I usually do.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my current financial situation.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to meet my monthly expenses .....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel financially stressed.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about keeping my job and income, including work at home.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My cancer or treatment has reduced my satisfaction with my present financial situation.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel in control of my financial situation.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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# NCCN Distress Thermometer and Problems List for Patients

Please complete the survey below.

Thank you!

Instructions: Please select the number between 0-10 that best describes how much distress you have been experiencing in the past week including today.

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

Please indicate if any of the following has been a problem for you in the past week including today.

## Practical Problems

Housing ☐ Yes ☐ No

Insurance/financial ☐ Yes ☐ No

Transportation ☐ Yes ☐ No

Work/school ☐ Yes ☐ No

Treatment decisions ☐ Yes ☐ No

## Family Problems

Dealing with children ☐ Yes ☐ No

Dealing with partner ☐ Yes ☐ No

Family health issues ☐ Yes ☐ No

## Emotional Problems

Depression ☐ Yes ☐ No

Fears ☐ Yes ☐ No

Nervousness ☐ Yes ☐ No

Sadness ☐ Yes ☐ No

Worry	<input type="radio"/> Yes	<input type="radio"/> No
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Loss of interest in usual activities	<input type="radio"/> Yes	<input type="radio"/> No
--------------------------------------	---------------------------	--------------------------

**Spiritual/religious concerns**

Spiritual/religious concerns	<input type="radio"/> Yes	<input type="radio"/> No
------------------------------	---------------------------	--------------------------

**Physical Problems**

Appearance	<input type="radio"/> Yes	<input type="radio"/> No
------------	---------------------------	--------------------------

Bathing/dressing	<input type="radio"/> Yes	<input type="radio"/> No
------------------	---------------------------	--------------------------

Breathing	<input type="radio"/> Yes	<input type="radio"/> No
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Changes in urination	<input type="radio"/> Yes	<input type="radio"/> No
----------------------	---------------------------	--------------------------

Constipation	<input type="radio"/> Yes	<input type="radio"/> No
--------------	---------------------------	--------------------------

Diarrhea	<input type="radio"/> Yes	<input type="radio"/> No
----------	---------------------------	--------------------------

Eating	<input type="radio"/> Yes	<input type="radio"/> No
--------	---------------------------	--------------------------

Fatigue	<input type="radio"/> Yes	<input type="radio"/> No
---------	---------------------------	--------------------------

Feeling Swollen	<input type="radio"/> Yes	<input type="radio"/> No
-----------------	---------------------------	--------------------------

Fevers	<input type="radio"/> Yes	<input type="radio"/> No
--------	---------------------------	--------------------------

Getting around	<input type="radio"/> Yes	<input type="radio"/> No
----------------	---------------------------	--------------------------

Indigestion	<input type="radio"/> Yes	<input type="radio"/> No
-------------	---------------------------	--------------------------

Memory/concentration	<input type="radio"/> Yes	<input type="radio"/> No
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Mouth sores	<input type="radio"/> Yes	<input type="radio"/> No
-------------	---------------------------	--------------------------

Nausea	<input type="radio"/> Yes	<input type="radio"/> No
--------	---------------------------	--------------------------

Nose dry/congested	<input type="radio"/> Yes	<input type="radio"/> No
--------------------	---------------------------	--------------------------

Pain	<input type="radio"/> Yes	<input type="radio"/> No
------	---------------------------	--------------------------

Sexual	<input type="radio"/> Yes	<input type="radio"/> No
--------	---------------------------	--------------------------

Skin dry/itchy	<input type="radio"/> Yes	<input type="radio"/> No
----------------	---------------------------	--------------------------

Sleep	<input type="radio"/> Yes	<input type="radio"/> No
-------	---------------------------	--------------------------

Substance abuse	<input type="radio"/> Yes	<input type="radio"/> No
-----------------	---------------------------	--------------------------

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Tingling in hands/feet

☐ Yes ☐ No

---

Adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines

# PHQ-9

Please complete the survey below.

Thank you!

**Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(select one number on each line)**

**How often during the past 2 weeks were you bothered by....**

	Not at all 0	Several days 1	More than half the days 2	Nearly every day 3
1. Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Trouble falling or staying asleep, or sleeping too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Feeling tired or having little energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Poor appetite or overeating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Trouble concentrating on things, such as reading the newspaper or watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Moving or speaking so slowly that other people could have noticed. Or the opposite--being so fidgety or restless that you have been moving around a lot more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Thoughts that you would be better off dead or of hurting yourself in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Score

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# Service Satisfaction Scale of Cancer Care for PT(SSS-PT)

Please complete the survey below.

Thank you!

---

Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your overall experience during the last year with care or therapy that you have received related to your cancer therapy or its side effects. By "practitioner" we mean the one or more doctors, clinicians, etc., who have worked with you in your cancer- related care.

**What is your overall feeling about the . . .**

	Completely Satisfied	Very Satisfied	Somewhat Satisfied	Mixed	Somewhat Unsatisfied	Very Unsatisfied	Completely Unsatisfied
Effect of health care services in helping you deal with your cancer and maintain your well being?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Professional knowledge and competence of your main cancer practitioner(s)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability of your main cancer practitioner(s) to listen and respond to your concerns or problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal manner of the main cancer practitioner(s) seen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waiting time between asking to be seen or treated and the appointment given?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Waiting time when you come for an appointment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of appointment times that fit your schedule?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effect of cancer treatment in preventing cancer progression or recurrence?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well your confidentiality and rights as an individual have been protected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of cancer care you have received?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of information on how to get the most out of the cancer care and related services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Explanations of specific procedures and treatment approaches used?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effect of services in helping relieve symptoms or reduce problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoroughness of the main cancer practitioner(s) you have seen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Helpfulness of the information  
provided about your cancer and  
its treatment?

☐☐☐☐☐☐☐☐

In an overall general sense, how  
satisfied are you with the cancer  
treatment you have received?

☐☐☐☐☐☐☐☐

# Income And Insurance

Please complete the survey below.

Thank you!

**The next questions are about health insurance and health benefits because those things may affect the kind of care and treatment you get for your prostate cancer, or your health and well being overall. We will NOT contact your insurance company or tell them any of your answers.**

Since our last interview, have you had any kind of health insurance or health benefits?

This includes: Medicare, Medicaid or other public assistance programs, military insurance or VA health benefits, private insurance (through a job or union, or that you paid for yourself), and any other kind of health insurance you might have.

- ☐ ALL of the time
- ☐ PART of the time
- ☐ NONE of the time
- ☐ I don't know

---

Do you have any kind of health insurance or health benefits now?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

Please specify, why didn't you have the insurance?

\_\_\_\_\_

---

Since our last interview, have you had any of the government-sponsored health insurance plans?

- ☐ Yes
- ☐ No

---

Since our last interview, have you had any of the MILITARY or VA health insurance plans or benefits?

- ☐ Yes
- ☐ No

---

Since our last interview, did you have any OTHER kind of health insurance, besides Government-sponsored and MILITARY or VA health insurance?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If Yes, please tell us what kind?

\_\_\_\_\_

**The next questions are about the health insurance or health benefits you have NOW. If you do NOT have health insurance or benefits now, think about the last health insurance plan you had.**

Since our last interview, about how much money have you paid out of your own pocket for your medical care? Include money for doctors, dentists, eye glasses, hearing aides, and medicine.

- ☐ Less than \$500
- ☐ \$500 - \$999
- ☐ \$1,000 - \$1,999
- ☐ \$2,000 - \$2,999
- ☐ \$3,000 - \$4,999
- ☐ \$5,000 - \$6,999
- ☐ \$7,000 - \$9,999
- ☐ \$10,000 - \$11,999
- ☐ \$12,000 - \$13,999
- ☐ \$14,000 - \$15,999
- ☐ \$16,000 - \$17,999
- ☐ \$18,000 - \$19,999
- ☐ \$20,000 - \$24,999
- ☐ \$25,000 - \$29,999
- ☐ \$30,000 or more
- ☐ I don't know

Overall, how HAPPY or UNHAPPY are you with your health insurance or health benefits? Choose a number from 1 to 5, where 1 means your are Very UNHAPPY and 5 means you are Very HAPPY.

- ☐ 1 (Very Unhappy)
- ☐ 2
- ☐ 3 (Not Unhappy or Happy)
- ☐ 4
- ☐ 5 (Very Happy)

Please specify

\_\_\_\_\_

**The next questions are about your work and income. Your answers will help us understand how easy it is for you to get health care, and how prostate cancer has affected your life.**

Which of the following best describes what you do now?

- ☐ Full time paid work
- ☐ Part time paid work
- ☐ looking for work
- ☐ Unemployed now, but have a job to return to
- ☐ Unable to work because of PROSTATE CANCER or treatment
- ☐ Unable to work because of OTHER HEALTH PROBLEMS
- ☐ Retired because of disability or illness due to PROSTATE CANCER or treatment
- ☐ Retired because of disability or illness due to OTHER HEALTH PROBLEMS
- ☐ Retired because of age
- ☐ Retired by choice
- ☐ I don't know
- ☐ Other

Please specify

\_\_\_\_\_

---

What is your current annual household income before you pay taxes? Count all kinds of income including: government benefits like Social Security, as well as work or farm income, and include your own income and any other person's income that goes toward your household expenses.

- ☐ Less than \$10,400 a year.... (or less than \$867 a month)
- ☐ \$10,401 - \$14,000 a year.... (or \$868 - \$1,167 a month)
- ☐ \$14,001 - \$17,600 a year.... (or \$1,168 - \$1,467 a month)
- ☐ \$17,601 - \$21,200 a year.... (or \$1,468 - \$1,767 a month)
- ☐ \$21,201 - \$24,800 a year.... (or \$1,768 - \$2,067 a month)
- ☐ \$24,801 - \$28,400 a year.... (or \$2,068 - \$2,367 a month)
- ☐ \$28,401 - \$32,000 a year.... (or \$2,368 - \$2,667 a month)
- ☐ \$32,001 - \$35,600 a year.... (or \$2,668 - \$2,967 a month)
- ☐ \$35,601 - \$39,200 a year.... (or \$2,968 - \$3,267 a month)
- ☐ \$39,201 - \$45,000 a year .... (or \$3,268 - \$3,750 a month)
- ☐ \$45,001 - \$50,000 a year.... (or \$3,751 - \$4,167 a month)
- ☐ \$50,001 - \$55,000 a year.... (or \$4,168 - \$4,583 a month)
- ☐ \$55,001 - \$60,000 a year.... (or \$4,584 - \$5,000 a month)
- ☐ \$60,001 - \$70,000 a year.... (or \$5,001 - 5,833 a month)
- ☐ \$70,001 - \$80,000 a year.... (or \$5,834 - \$6,667 a month)
- ☐ \$80,001 or more a year.... (or \$6,668 or more a month)
- ☐ I don't know

---

Including yourself, how many people are supported by this income?

- ☐ 1 person, I am the only person supported by this income
- ☐ 2 people
- ☐ 3 people
- ☐ 4 people
- ☐ 5 people
- ☐ 6 people
- ☐ 7 people
- ☐ 8 people
- ☐ 9 or more people
- ☐ I don't know

---

Sometimes people put off getting medical care that they need. Since our last interview, have you had to delay getting medical care?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If YES, did you put off getting medical care for any of the following reasons? Check ALL that apply.

- ☐ I couldn't get through on the telephone
- ☐ I couldn't get an appointment soon enough
- ☐ I would have to wait too long at the doctor's office
- ☐ The clinic or doctor's office wasn't open when I could get there
- ☐ I couldn't take time off from work to go
- ☐ I didn't have any way to get there
- ☐ I couldn't afford the cost of transportation to get there
- ☐ I couldn't afford the cost of the visit
- ☐ I couldn't afford the medicine or treatments
- ☐ I don't know
- ☐ Other

# Physical Health And Health Behavior

Please complete the survey below.

Thank you!

---

Since our last interview, who has given you emotional support? Check ALL that apply.

- ☐ Wife or Partner
- ☐ Daughter or Son
- ☐ Sister or Brother
- ☐ Mother or Father
- ☐ Other relative
- ☐ Friend(s)
- ☐ Neighbor(s)
- ☐ Co-worker(s)
- ☐ Church Member(s)
- ☐ Priest, or other religious advisor
- ☐ God
- ☐ Club member(s)
- ☐ Prostate cancer support group
- ☐ Your doctor or doctors
- ☐ A counselor or therapist
- ☐ No one
- ☐ I don't know
- ☐ Other

---

Please specify \_\_\_\_\_

---

In general, how many close friends do you have? A "close friend" would be anyone you feel at ease with, can talk to about private things, and can call on for help. This could include your wife or other relatives, as well as friends who are not relatives.

- ☐ No one
- ☐ 1-3
- ☐ 4 - 5
- ☐ 6 - 7
- ☐ 8 or more

## SMOKING AND DRINKING

Since our last interview, have you smoked cigarettes at least once a day at any time?

- ☐ Yes
- ☐ No
- ☐ I don't know

---

If YES, about how many cigarettes did you smoke on a normal day?

- ☐ 1 - 2
- ☐ 3 - 5
- ☐ 6 - 10
- ☐ 11 - 15
- ☐ 16 - 20
- ☐ 21 - 30 (1 - 1 1/2 packs a day)
- ☐ 31 - 40 (1 1/2 - 2 packs a day)
- ☐ More than 2 packs a day
- ☐ I don't know

---

If YES, do you smoke cigarettes at least once a day now?

- ☐ Yes  
☐ No  
☐ I don't know

---

Do you use any of the products listed below at least once a day now?

- ☐ Chewing tobacco  
☐ Cigars  
☐ Snuff  
☐ Pipe

---

How often do you drink beer?

- ☐ NEVER  
☐ Once a month or less  
☐ 2 - 3 times a month  
☐ 1 - 2 times a week  
☐ 3 - 4 times a week  
☐ 5 - 6 times a week  
☐ Every day

---

If you drink beer, how much do you usually drink?

- ☐ Less than 1 can or bottle (12 oz.)  
☐ 1 - 2 cans or bottles  
☐ 3 or more cans or bottles

---

How often do you drink wine or wine coolers?

- ☐ NEVER  
☐ Once a month or less  
☐ 2 - 3 times a month  
☐ 1 - 2 times a week  
☐ 3 - 4 times a week  
☐ 5 - 6 times a week  
☐ Every day

---

If you drink wine or wine coolers, how much do you usually drink?

- ☐ Less than 1 glass  
☐ 1 - 2 glasses  
☐ More than 2 glasses

---

How often do you drink liquor or mixed drinks?

- ☐ NEVER  
☐ Once a month or less  
☐ 2 - 3 times a month  
☐ 1 - 2 times a week  
☐ 3 - 4 times a week  
☐ 5 - 6 times a week  
☐ Every day

---

If you drink liquor or mixed drinks, how much do you usually drink?

- ☐ Less than 1 shot of liquor  
☐ 1 - 3 shots of liquor  
☐ More than 3 shots of liquor

---

**The next questions are about your USUAL EXERCISE and PHYSICAL ACTIVITY. Please do NOT include work you did as part of your job.**

In the past 12 months, did you do any LIGHT exercise that didn't make you breathe any harder than usual at least once a week?

NOTE: "Light exercise" includes things like light yard work (gardening or pruning), light house work (dusting or vacuuming), playing golf with a cart, very easy bicycling or swimming, or light stretching.

- ☐ Yes  
☐ No  
☐ I don't know

---

If YES, how many days a week did you do any kind of LIGHT exercise?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days

---

If YES, how many hours a day did you do any kind of LIGHT exercise?

- ☐ Less than 1 hour  
☐ 1 - 2 hours  
☐ 3 hours or more

---

In the past 12 months, did you do MODERATE exercise that made you breathe somewhat harder than usual, at least once a week?

NOTE: "Moderate exercise" includes things like brisk walking or running, golfing without a cart or caddy, recreational swimming, moderate yard work (mowing with a power mower), doubles tennis, ballroom dancing, low impact or water aerobics, moderate housework (scrubbing floors or washing windows), or slow bicycling on level ground.

- ☐ Yes  
☐ No  
☐ I don't know

---

If YES, how many days a week did you do any kind of MODERATE exercise?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days

---

If YES, how many minutes a day did you do any kind of MODERATE exercise?

- ☐ 10 - 25 minutes  
☐ 30 - 40 minutes  
☐ 45 - 55 minutes  
☐ 60 minutes or more

---

In the past 12 months, did you do VIGOROUS exercise that made you breathe much harder than usual, at least once a week?

NOTE: "Vigorous exercise" includes things like race-walking, jogging or running, aerobics, swimming laps, using a push mower, singles tennis, racquetball or squash, fast or steep hill bicycling, heavy housework, circuit training, stair machine, clogging or line dancing.

- ☐ Yes  
☐ No  
☐ I don't know

---

If YES, how many days a week did you do any kind of VIGOROUS exercise?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days

---

If YES, how many minutes a day did you do any kind of VIGOROUS exercise?

- ☐ 10 - 25 minutes
- ☐ 30 - 40 minutes
- ☐ 45 - 55 minutes
- ☐ 60 minutes or more

---

### FINAL QUESTION

Do you have any other comments or suggestions?

---

"The PHQ-9 in the survey you have completed screens for depression, but please advise that this is not a diagnosis of your current mental health status. Please visit the National Alliance on Mental Illness website (<https://www.nami.org>) for more information on resources and services available or call the Suicide Prevention Lifeline at 1-800-273-8255 if you need immediate support."

PCaP ID (To be filled by PCaP staff)

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Before you begin the survey, please write today's date, your name, date of birth, and address in the boxes below. Please write as clearly as you can.

Today's Date: 

--	--

 / 

--	--

 / 

--	--

First Name

Last Name

Number & Street Address

City

State

Zip Code

May we contact you by email?

☐ Yes

☐ No

If yes, what is your email address?

--

May we contact you by phone?

☐ Yes

☐ No

If yes, please write your phone number in the box below

( 

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 ) 

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May we contact you at work?

☐ Yes

☐ No

If yes, please write your phone number in the box below

( 

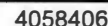
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**Last Name**

$$( \begin{array}{|c|c|c|} \hline & & \\ \hline \end{array} ) \begin{array}{|c|c|c|} \hline & & \\ \hline \end{array} - \begin{array}{|c|c|c|} \hline & & \\ \hline \end{array}$$
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$$\left( \begin{array}{|c|c|c|} \hline & & \\ \hline \end{array} \right) \begin{array}{|c|c|c|} \hline & & \\ \hline \end{array} - \begin{array}{|c|c|c|c|} \hline & & & \\ \hline \end{array}$$

\_\_\_\_\_

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Page 2 of 57



4058406

**3. Since you were diagnosed with prostate cancer, have you moved?**

- ☐ Yes
- ☐ No
- ☐ I don't know

**3a. If yes, why did you move? Check ALL that**

- ☐ To live in a new or better house or location
- ☐ To be closer to my doctor or clinic
- ☐ To be closer to my family
- ☐ To be closer to my friends
- ☐ So I could get help with daily activities
- ☐ So I could get help with medical care
- ☐ So my wife or partner could get help with daily activities
- ☐ So my wife or partner could get medical care
- ☐ To cut costs
- ☐ Because I could not afford to pay my rent, mortgage, property taxes or other expenses
- ☐ I don't know
- ☐ Other (write your answer in the box)

**4. Which of the following best describes where you live now?**

- ☐ Your own home or apartment
- ☐ A relative's home or apartment
- ☐ A friend's home or apartment
- ☐ A continuing care facility where you are living
- ☐ A nursing home or other group facility where
- ☐ A shelter
- ☐ A hospice
- ☐ Some other living arrangement
- ☐ I don't have a regular living place



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**5. Do you own or partly own the place where you live?**

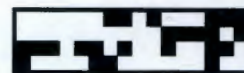
- ☐ Yes
- ☐ No
- ☐ I don't know

**6. How many other people live with you?**

- ☐ 1
- ☐ 2
- ☐ 3-4
- ☐ 5-6
- ☐ 7-10
- ☐ More than 10
- ☐ I don't know

**6a. If you live with other people, what relation are they to you?**

- ☐ Wife or partner
- ☐ One or more dependent children
- ☐ One or more adult children
- ☐ Other relatives
- ☐ Friend(s)
- ☐ Paid caregiver(s)
- ☐ Other
- ☐ I don't know



4058406

**7. We would like to ask who has helped you with your care the most?****Name****Relationship****Address****City****State****Zip****Email****Home Phone Number**

(	<input type="text"/>	<input type="text"/>	<input type="text"/>	)	<input type="text"/>	<input type="text"/>	<input type="text"/>	-	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
---	----------------------	----------------------	----------------------	---	----------------------	----------------------	----------------------	---	----------------------	----------------------	----------------------	----------------------

**Cell Phone Number**

(	<input type="text"/>	<input type="text"/>	<input type="text"/>	)	<input type="text"/>	<input type="text"/>	<input type="text"/>	-	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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**7a. How long have you known your primary caregiver? (In years)**

<input type="text"/>	<input type="text"/>
----------------------	----------------------

**7b. How long has this person been your caregiver? (In years)**

<input type="text"/>	<input type="text"/>
----------------------	----------------------

**7c. On average, how many hours in a day does s/he spend taking care of you?**

<input type="text"/>	<input type="text"/>
----------------------	----------------------

**7d. Please select all types of care you get from your caregiver**

- ☐ Help with activities of daily living
- ☐ Help with instrumental of activities of daily living
- ☐ Help with communicating with health care professionals, monitoring severity...



**INSTRUCTIONS:** Please tell us your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.

**In general, would you say your health is:**

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

**The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

**Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf**

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, not limited at all

**Climbing several flights of stairs**

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, not limited at all

**During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

**Accomplished less than you would like**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**Were limited in the kind of work or other activities**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time



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During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

**Accomplished less than you would like**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**Were limited in the kind of work or other activities**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time



4058406

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

**Have you felt calm and peaceful?**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**Did you have a lot of energy?**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**Have you felt downhearted and depressed?**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

**During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

## Charlson Comorbidity Index



4058406

Below is the list of some health conditions. Please check the box if you have been diagnosed with any of these conditions.

Comorbidity (Choose all that are present)

- ☐ Myocardial infarction
- ☐ Congestive heart failure
- ☐ Peripheral vascular disease
- ☐ Cerebrovascular disease (except hemiplegia)
- ☐ Dementia
- ☐ Chronic pulmonary disease
- ☐ Connective tissue disease
- ☐ Ulcer disease
- ☐ Mild liver disease
- ☐ Diabetes (without complications)
- ☐ Diabetes with end organ damage
- ☐ Hemiplegia
- ☐ Moderate or severe renal disease
- ☐ Solid tumor (non metastatic)
- ☐ Leukemia
- ☐ Lymphoma, Multiple myeloma
- ☐ Moderate or severe liver disease
- ☐ Metastatic solid tumor
- ☐ AIDS

Do you have any other health problems?

☐ No ☐ Yes If Yes, please specify

## Medical Section



4058406

The next questions are about your prostate cancer and the care you have gotten since you were diagnosed with prostate cancer

**NOTE:** When we ask about prostate cancer "treatment", that can mean Surgery (removal of your prostate), Radiation, Watchful Waiting, Pills or Shots, etc...

1a. How long has it been since your last PSA test? Choose ONE answer.

- |  |  |
|--|--|
| <input type="checkbox"/> Less than 1 month | <input type="checkbox"/> 11 - 12 months    |
| <input type="checkbox"/> 1 - 2 months      | <input type="checkbox"/> 1 - 1-1/2 years   |
| <input type="checkbox"/> 3 - 4 months      | <input type="checkbox"/> 1-1/2 - 2 years   |
| <input type="checkbox"/> 5 - 6 months      | <input type="checkbox"/> More than 2 years |
| <input type="checkbox"/> 7 - 8 months      | <input type="checkbox"/> I don't know      |
| <input type="checkbox"/> 9 - 10 months     |  |

1b. Do you know if your PSA level was undetectable last time you were tested?

- ☐ Yes  
☐ No

1c. Do you remember the name of your doctor who did your last PSA test?

- ☐ Yes  
☐ No

If YES, write the name of doctor

1d. Do you remember the name of HOSPITAL/CLINIC/LAB where you had PSA test?

- ☐ Yes  
☐ No

If YES, write the name of hospital/clinic/lab

1e. Do you remember the address of HOSPITAL/CLINIC/LAB where you had PSA test?

- ☐ Yes  
☐ No

If YES, write the address of hospital/clinic/lab

Street

City

State

Zip



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2. Since our last interview, have you been followed up regarding prostate cancer?

- ☐ Yes
- ☐ No
- ☐ I don't know

If no, skip to question #1,  
page #14

2a. Please write the name of doctor who treated you

2b. Please write the name of hospital where you had your treatment

2c. Please write the address of hospital/clinic where you had your treatment

Street

City

State

Zip

2d. What other kinds of doctors or health care professionals have you talked to about your prostate cancer or treatment? Check ALL that apply.

- ☐ A urologist
- ☐ A radiation oncologist
- ☐ A medical oncologist
- ☐ I don't know
- ☐ Other (write your answer in the box)

2e. Who are you seeing for your primary health care?

Name of Doctor

Name of Hospital

Please write the address of hospital/clinic/lab in the boxes

Street

City

State

Zip

Is this person monitoring your PSA?

- ☐ Yes
- ☐ No



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**2f. Since our last interview, have you had any of the following procedures or tests?**

**Check ALL that apply.**

- ☐ A trans-rectal ultrasound examination of your prostate
- ☐ Bone Scan
- ☐ MRI
- ☐ CT Scan
- ☐ I don't know
- ☐ None

**2g. Since our last interview, have you participated in any clinical trials to test new prostate cancer treatments?**

- ☐ Yes, one clinical trial
- ☐ Yes, more than one clinical trial
- ☐ No
- ☐ I don't know

**2h. How long has it been since your last Digital Rectal Exam (DRE)? Choose ONE answer**

- ☐ Less than 1 month
- ☐ 1 - 2 months
- ☐ 3 - 4 months
- ☐ 5 - 6 months
- ☐ 7 - 8 months
- ☐ 9 - 10 months
- ☐ 11 - 12 months
- ☐ 1 - 1-1/2 years
- ☐ 1-1/2 - 2 years
- ☐ More than 2 years
- ☐ I don't know

**2i. Since our last interview, have you had a follow-up biopsy of your prostate taken with a needle through your rectum?**

- ☐ Yes
- ☐ No
- ☐ I don't know

**2j. How long has it been since your last follow-up biopsy? Choose ONE answer.**

- ☐ Less than 1 month
- ☐ 1 - 2 months
- ☐ 3 - 4 months
- ☐ 5 - 6 months
- ☐ 7 - 8 months
- ☐ 9 - 10 months
- ☐ 11 - 12 months
- ☐ 1 - 1-1/2 years
- ☐ 1-1/2 - 2 years
- ☐ More than 2 years
- ☐ I don't know



4058406

3. Since our last interview, did you have to make a **NEW** decision about what to do about your prostate cancer? (This could be deciding whether to have a new kind of treatment, whether to keep having or stop treatment you were already having, etc.)

- ☐ Yes  
☐ No  
☐ I don't know

3a. Since our last interview, between you and your doctor, who was mostly responsible for deciding what to do about your prostate cancer when you first diagnosed?

Choose **ONE** answer.

- ☐ I was mostly responsible for deciding what to do  
☐ My doctor and i were both responsible  
☐ My doctor was mostly responsible for deciding what to do  
☐ I don't know

4. How much do you agree or disagree with the following statements about the treatment decisions you made when you were first diagnosed with prostate cancer?

Please choose a number 1 to 5, where 1 means you **Strongly DISAGREE** and 5 means you **Strongly AGREE** with the statement.

had all the information I needed to make a decision about treatment.

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
Strongly DISAGREE      ←      Don't Agree or Disagree      →      Strongly AGREE

My doctors told me the whole story about side effects of treatment.

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
Strongly DISAGREE      ←      Don't Agree or Disagree      →      Strongly AGREE

knew the right questions to ask the doctor about treatment.

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
Strongly DISAGREE      ←      Don't Agree or Disagree      →      Strongly AGREE

had enough time to make a decision about treatment.

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
Strongly DISAGREE      ←      Don't Agree or Disagree      →      Strongly AGREE

am satisfied with the treatment choices I made.

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
Strongly DISAGREE      ←      Don't Agree or Disagree      →      Strongly AGREE



4058406

The next questions are about your health and the quality of your life as a prostate cancer survivor. We know that many of these questions are personal, but your answers are important to help us understand why life is better for some men with prostate cancer than it is for others.

**1. Since our last interview, have you had any problems with urination?**

- ☐ Yes  
☐ No  
☐ I don't know

If no, skip to question #2

**1a. If YES, have you had any of the problems listed below? Check ALL that apply.**

- ☐ Difficulty passing urine  
☐ Frequent or urgent urination  
☐ Problems with leaking urine (incontinence)  
☐ Pain during urination  
☐ Blood in urine  
☐ I don't know  
☐ Other urination problem (write your answer in the box)

**1b. Have you talked to a doctor about problems with urination since our last interview?**

- ☐ Yes  
☐ No  
☐ I don't know

**2. Since our last interview, have you had any problems with erections or your sexual function?**

- ☐ Yes  
☐ No  
☐ I don't know



This questionnaire is designed to measure Quality of Life issues in patients with Prostate cancer. To help us get the most accurate measurement, it is important that you answer all questions honestly and completely. Remember, as with all medical records, information contained within this survey will remain strictly confidential.

Over the past 4 weeks, how often have you leaked urine?

- ☐ More than once a day
- ☐ About once a day
- ☐ More than once a week
- ☐ About once a week
- ☐ Rarely or never

Which of the following best describes your urinary control during the last 4 weeks?

- ☐ No urinary control whatsoever
- ☐ Frequent dribbling
- ☐ Occasional dribbling
- ☐ Total control

How many pads or adult diapers per day did you use to control leakage during the last 4 weeks?

- ☐ None
- ☐ 1 per day
- ☐ 2 per day
- ☐ 3 or more per day

How big a problem, if any, has each of the following been for you?  
"0" being No Problem and "4" being Big Problem

Dripping or leaking urine.

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
 No Problem   ←———— Small Problem —————→ Big Problem

Pain or burning on urination.

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
 No Problem   ←———— Small Problem —————→ Big Problem

Bleeding with urination.

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
 No Problem   ←———— Small Problem —————→ Big Problem





4058406

**Weak urine stream or incomplete emptying**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**Need to urinate frequently during the day**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**Overall, how big a problem has your urinary function been for you during the last 4 weeks?**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**How big a problem, if any, has each of the following been for you?****Urgency to have a bowel movement**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**Increased frequency of bowel movements**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**Losing control of your stools**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**Bloody stools**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem



4058406

**Abdominal/Pelvic/Rectal pain**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**Overall, how big a problem have your bowel habits been for you during the last 4 weeks?**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem   ←———— Small Problem   →———— Big Problem

**How would you rate each of the following during the last 4 weeks?****Your ability to have an erection?**

- ☐ Very poor to none
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good

**Your ability to reach orgasm (climax)?**

- ☐ Very poor to none
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good

**How would you describe the usual QUALITY of your erections during the last 4 weeks?**

- ☐ None at all
- ☐ Not firm enough for any sexual activity
- ☐ Firm enough for masturbation and foreplay only
- ☐ Firm enough for intercourse



4058406

**How would you describe the FREQUENCY of your erections during the last 4 weeks?**

- ☐ I NEVER had an erection when I wanted one
- ☐ I had an erection LESS THAN HALF the time I wanted one
- ☐ I had an erection ABOUT HALF the time I wanted
- ☐ I had an erection MORE THAN HALF the time I wanted one
- ☐ I had an erection WHENEVER I wanted one

**Overall, how would you rate your ability to function sexually during the last 4 weeks?**

- ☐ Very Poor
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good

**Overall, how big a problem has your sexual function or lack of sexual function been for you during the last 4 weeks?**

- ☐ No Problem
- ☐ Very small problem
- ☐ Small problem
- ☐ Moderate problem
- ☐ Big problem

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*Wei J, Dunn R, Litwin M, Sandler H, and Sanda M. "Development and Validation of the Expanded Prostate Cancer Index Composite (EPIC) for Comprehensive Assessment of Health-Related Quality of Life in Men with Prostate Cancer", Urology. 56: 899-905, 2000.*



4058406



How big a problem during the last 4 weeks, if any, has each of the following been for you?

**Hot flashes**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem      ←———— Small Problem      →———— Big Problem

**Breast tenderness/enlargement**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem      ←———— Small Problem      →———— Big Problem

**Feeling depressed**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem      ←———— Small Problem      →———— Big Problem

**Lack of energy**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem      ←———— Small Problem      →———— Big Problem

**Change in body weight**

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
No Problem      ←———— Small Problem      →———— Big Problem

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Wei J, Dunn R, Litwin M, Sandler H, and Sanda M. "Development and Validation of the Expanded Prostate Cancer Index Composite (EPIC) for Comprehensive Assessment of Health-Related Quality of Life in Men with Prostate Cancer", *Urology*.56: 899-905, 2000.



**Medical Expenditure Panel Survey (MEPS)**

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**1. Are you currently being treated for cancer - that is are you planning or recovering from cancer surgery, or receiving chemotherapy, radiation therapy, or hormonal therapy for your cancer?**

☐ Yes

☐ No

**If yes, skip to question #2,  
page #21**

**1a. If no, to the best of your knowledge, are you now free of cancer?**

☐ Yes

☐ No

☐ I don't know

**1b. About how long ago did you receive your last cancer treatment?**

☐ Less than 1 year ago

☐ 1 year ago to less than 3 years ago

☐ 3 years ago to less than 5 years ago

☐ 5 years ago to less than 10 years ago

☐ 10 years ago to 20 years ago

☐ More than 20 years ago

☐ I have not been treated for cancer

**1c. Did a doctor or other health professional ever tell you that your cancer had come back?**

☐ Yes

☐ No

**1c1. If yes, what was the most recent year a doctor or health professional told you that your cancer had come back?**

**1c2. Is this the first time you have been treated for any type of cancer?**

☐ Yes

☐ No



### Changes to your work schedule

These next questions ask about different ways cancer, its treatment, or the lasting effects of that treatment may have affected your work that is, your hours, duties, or employment status. As you answer these questions, please think about the entire time from when you were first diagnosed with cancer to now. If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

2. At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business?

☐ Yes

☐ No → If no, skip to question #15,  
page #27

3. At any time since your first cancer diagnosis, did you TAKE extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

☐ Yes

☐ No

3a. If no, at any time since your first cancer diagnosis, did you ASK extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

☐ Yes

☐ No

3a1. If yes, did you ask for these work changes...

☐ Because of your cancer, its treatment or its lasting effects?

☐ Some other reasons

3a2. Did you ever take extended paid time off from work (vacation, sick time and/or disability leave)? By extended time off, we mean more than an occasional day of here and there.

☐ Yes

☐ No → If no, skip to question #18,  
page #28



4058406

**When did you take extended paid time off from work? Mark all that apply.**

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

**What do you estimate was the total amount of extended paid time off from work that you took?**

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

**Is your extended paid time off from work ongoing?**

- ☐ Yes
- ☐ No

**Did you ever take unpaid time off from work?**

- ☐ Yes
- ☐ No

**When did you take unpaid time off from work? Mark all that apply.**

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

**What do you estimate was the total amount of unpaid time off from work that you took?**

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years



4058406

**Is your unpaid time off ongoing?**

☐ Yes

☐ No

**3a3. Did you ever change from working part-time to working fulltime?**

☐ Yes

☐ No

**When did you change from working part-time to working fulltime? Mark all that apply.**

☐ At the time of diagnosis

☐ During treatment

☐ Less than one year after treatment was finished

☐ One year or more after treatment was finished

**What do you estimate was the total amount of time you worked full-time?**

☐ Less than 2 months

☐ 2 months to less than 6 months

☐ 6 months to less than 1 year

☐ 1 year to 3 years

☐ More than 3 years

**Is this change ongoing?**

☐ Yes

☐ No

**3a4. Did you ever change from working full time to working part-time?**

☐ Yes

☐ No

**When did you change from working part-time to working fulltime? Mark all that apply.**

☐ At the time of diagnosis

☐ During treatment

☐ Less than one year after treatment was finished

☐ One year or more after treatment was finished

**What do you estimate was the total amount of time you worked part-time?**

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

**Is this change ongoing?**

- ☐ Yes
- ☐ No

**3a5. Did you ever change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day-to-day?**

- ☐ Yes
- ☐ No

**When did you change to a flexible work schedule? Mark all that apply.**

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished

**Did you ever change to a less demanding job?**

- ☐ Yes
- ☐ No

**When did you change to a less demanding job? Mark all that apply.**

- ☐ At the time of diagnosis
- ☐ During treatment
- ☐ Less than one year after treatment was finished
- ☐ One year or more after treatment was finished



4058406

**How long did you stay in the less demanding job?**

- ☐ Less than 2 months
- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

**Is this change ongoing?**

- ☐ Yes
- ☐ No

**l. Did you make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?**

- ☐ Yes
- ☐ No

**If yes, please describe**

--

**m. Because of your cancer, its treatment, or the lasting effects of that treatment, did you ever decide not to pursue an advancement or promotion?**

- ☐ Yes
- ☐ No

**n. Because of your cancer, its treatment, or the lasting effects of that treatment, did you retire earlier than you had planned?**

- ☐ Yes
- ☐ No

**o. Because of your cancer, its treatment, or the lasting effects of that treatment, did you delay retirement beyond when you had planned?**

- ☐ Yes
- ☐ No



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### **Other Aspects of Work**

Please continue to think about all your work experiences from the time you were first diagnosed with cancer to now. If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

**8. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any physical tasks required by your job?**

☐ Yes

☐ No

☐ I was never required to perform physical tasks as part of my job

**9. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks required by your job?**

☐ Yes

☐ No

**10. Did you ever feel that, because of your cancer, its treatment, or the lasting effects of that treatment, you were less productive at work?**

☐ Yes

☐ No

**11. Did you ever worry that, because of the effects of cancer on your health, you might be forced to retire or quit work before you are ready?**

☐ Yes

☐ No

**12. Did you ever stay at a job in part because you were concerned about losing your health insurance?**

☐ Yes

☐ No

**13. Were you concerned about losing your health insurance because of your cancer?**

☐ Yes

☐ No



4058406

**14. Thinking about your work life or career, what effect has your experience with cancer, its treatment, or the lasting effects of that treatment had on it?**

- ☐ Mostly positive effect
- ☐ Mostly negative effect
- ☐ Equally positive and negative effect
- ☐ Neither positive nor negative effect

**15. Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?**

- ☐ Yes
- ☐ No
- ☐ Doesn't apply

**Following questions are related to you caregivers, please try to answer correctly as possible.**

**16. Since the time you were first diagnosed with cancer, has any friend or family member provided care to you during or after your cancer treatment?**

☐ Yes

☐ No

**If no, skip to question #24,  
page #30**

**16a. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties or employment status?**

☐ Yes

☐ No → Skip to question #20, page #29

☐ None of my caregivers were employed while caring for me → Skip to question #24, page #30

☐ I don't know → Skip to question #20, page #29

**16b. Did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties, or employment status for at least 2 months?**

☐ Yes

☐ No

**16c. Did any of your caregivers ever take extended paid time off from work (vacation and/or sick time)?**

☐ Yes

☐ No



4058406

**16d. How long do you estimate this caregiver took extended paid time off from work?**

- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

**16e. Is this caregiver's extended paid time off from work ongoing?**

- ☐ Yes
- ☐ No

**17. Did any of your caregivers take unpaid time off from work?**

- ☐ Yes
- ☐ No

**17a. How long do you estimate this caregiver took unpaid time off from work?**

- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years

**17b. Is this caregiver's unpaid time off ongoing?**

- ☐ Yes
- ☐ No

**18. Did any of your caregivers change from working part-time to working full-time?**

- ☐ Yes
- ☐ No

**18a. How long do you estimate this caregiver worked full-time?**

- ☐ 2 months to less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to 3 years
- ☐ More than 3 years



4058406

**18b. Is this change ongoing?**

☐ Yes

☐ No

**19. Did any of your caregivers' change from working full-time to working part time?**

☐ Yes

☐ No

**19a. How long do you estimate this caregiver worked part-time?**

☐ 2 months to less than 6 months

☐ 6 months to less than 1 year

☐ 1 year to 3 years

☐ More than 3 years

**19b. Is this change ongoing?**

☐ Yes

☐ No

**20. Did any of your caregivers make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?**

☐ Yes

☐ No

☐ I don't know

**Please specify**

--



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**21. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers change to a less demanding job?**

- ☐ Yes  
☐ No  
☐ I don't know

**22. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers retire early?**

- ☐ Yes  
☐ No  
☐ I don't know

**23. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers delay retirement?**

- ☐ Yes  
☐ No  
☐ I don't know

**Experiences with Health Insurance.**

The next few questions are about health insurance coverage from the time you were first diagnosed with cancer to now. If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

**24. At any time from when you were first diagnosed with cancer to now, were you covered by health insurance that paid for all or part of your medical care, tests or cancer treatment?**

- ☐ Yes  
☐ No  
☐ I don't know

**24a. If yes, was there ever a time when health insurance refused to cover a visit for your cancer to the doctor or facility of your choice?**

- ☐ Yes  
☐ No  
☐ Doesn't apply



4058406

**25. Was there ever a time when health insurance refused to cover a second opinion about your cancer?**

- ☐ Yes
- ☐ No
- ☐ I never asked for second opinion

**26. Were you ever denied health insurance coverage because of your cancer?**

- ☐ Yes
- ☐ No

**The Effects of Cancer and Treatment on Finances.**

The next questions ask about different kinds of financial burden you or your family may have experienced because of your cancer, its treatment, or the lasting effects of that treatment. Please continue to think about all the time from when you were first diagnosed with cancer to now. If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

**27. Have you or has anyone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of that treatment?**

- ☐ Yes
- ☐ No

**27a. How much did you or your family borrow, or how much debt did you incur because of your cancer, its treatment, or the lasting effects of that treatment?**

- ☐ Less than \$10,000
- ☐ \$10,000 to \$24,999
- ☐ \$25,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$100,000 or more

**27b. Did you or your family ever file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?**

- ☐ Yes
- ☐ No

**27c. Have you or your family had to make any other kinds of financial sacrifices because of your cancer, its treatment, or the lasting effects of that treatment?**

- ☐ Yes (If yes, please describe in the box)
- ☐ No



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**28. Have you ever worried about having to pay large medical bills related to your cancer?**

☐ Yes

☐ No

**29. Please think about medical care visits for cancer, its treatment, or the lasting effects of that treatment. Have you ever been unable to cover your share of the cost of those visits?**

☐ Yes

☐ No

**Medical Care for Cancer**

**These next questions ask about certain experiences you may have had when receiving medical care for cancer from the time you were first diagnosed to now. If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.**

**30. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you the need for regular follow-up care and monitoring even after completing your treatment?**

☐ Discussed it with me in detail

☐ Briefly discussed it with me

☐ Did not discuss it at all

☐ I don't remember

**31. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you late or long-term side effects of cancer treatment you may experience over time?**

☐ Discussed it with me in detail

☐ Briefly discussed it with me

☐ Did not discuss it at all

☐ I don't remember

**32. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you lifestyle or health recommendations such as diet, exercise, quitting smoking?**

☐ Discussed it with me in detail

☐ Briefly discussed it with me

☐ Did not discuss it at all

☐ I don't remember



4058406

33. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you your emotional or social needs related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Discussed it with me in detail  
☐ Briefly discussed it with me  
☐ Did not discuss it at all  
☐ I don't remember

34. At any time since you were first diagnosed with cancer, did you get all of the medical care, tests, or treatments that you or your doctor believed were necessary?

☐ Yes

☐ No

If yes, skip to question #36,  
page #34

34a. If no, which of these are reasons you did not get all of the medical care, tests, or treatments you or a doctor believed you needed? Mark yes or no for each item below.

Yes, a reason

No, not a reason

Couldn't afford care. . . . .

☐☐

Insurance company wouldn't approve or pay for care . .

☐☐

Doctor did not accept your insurance. . .

☐☐

Had problems getting to doctor's office.

☐☐

Couldn't get time off from work. . .

☐☐

Didn't know where to go to get care. .

☐☐

Couldn't get child care/adult care. . .

☐☐

Didn't have time, care/test/treatment took too long. .

☐☐

Other reason. . . . .

☐☐

If other reason, please specify in the box

If you answered 'Yes' to only one reason to the question above, GO TO next section, page number 34 question number 36 "the effects of cancer and its treatment on life in general". Otherwise (i.e. more than one reasons selected) please answer question number 35 in the next page.



4058406

**35. Which one of these is the main reason that you did not get all of the medical care, tests, or treatments you or a doctor believed you needed? Please choose ONE answer.**

- ☐ Couldn't afford care
- ☐ Insurance company wouldn't approve or pay for care
- ☐ Doctor didn't accept your insurance
- ☐ Had problems getting to the doctors' office
- ☐ Couldn't get time off from work
- ☐ Didn't know where to go to get care
- ☐ Couldn't get child care/adult care
- ☐ Didn't have time, care/test/treatment took too long
- ☐ Some other reason. (Please describe)

**The Effects of Cancer and Its Treatment on Life in General.**

The last few questions in this section ask about how your cancer, its treatment and the lasting effects of that treatment may have influenced certain parts of your life.

If you have had more than one type of cancer please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

**36. Did your cancer, its treatment, or the lasting effects of that treatment ever limit the kind or amount of activities you do outside of work, such as shopping, child care, exercising, studying, work around the house, and so on?**

- ☐ Yes
- ☐ No

**36a. If yes, how long were you or have you been limited in the kind or amount of usual daily activities?**

- ☐ Less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to less than 3 years
- ☐ 3 years to less than 5 years
- ☐ 5 years to less than 10 years
- ☐ More than 10 years



4058406

**36b. Is this limitation ongoing?**

☐ Yes

☐ No

**37. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform many mental tasks as part of your usual daily activities?**

☐ Yes

☐ No

**38. Have you ever asked for help getting to a doctor or other healthcare provider because of your cancer, its treatment, or the lasting effects of that treatment?**

☐ Yes

☐ No

**39. Did you ever receive help getting to a doctor or other healthcare provider?**

☐ Yes

☐ No

**40. Have you ever asked for help understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?**

☐ Yes

☐ No

**41. Did you ever receive help understanding health insurance or medical bills?**

☐ Yes

☐ No

**42. How often do you worry that your cancer may come back or get worse?**

☐ Never

☐ Rarely

☐ Sometimes

☐ Often

☐ All the time



4058406

43. How often do you worry that if your cancer came back or got worse it might keep you from fulfilling responsibilities at home or at work?

- ☐ Never  
☐ Rarely  
☐ Sometimes  
☐ Often  
☐ All the time

44. In your own opinion, what do you think are the chances that your cancer will come back or get worse within the next 10 years?

- ☐ Very low  
☐ Fairly low  
☐ Moderate  
☐ Fairly high  
☐ Very high  
☐ I don't know

45. Have any of the following been positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment?

Please mark Yes or No for each item below.

	Yes	No
a. It has made me a stronger	<input type="checkbox"/>	<input type="checkbox"/>
b. I can cope better with life's challenges. . . .	<input type="checkbox"/>	<input type="checkbox"/>
c. It became a reason to make positive	<input type="checkbox"/>	<input type="checkbox"/>
d. It has made me have healthier habits .	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us anything else about your experiences with cancer.



4058406

## Comprehensive Score for Financial Toxicity (COST)

Below is a list of statements that other people with your illness have said are important. Please mark one number per line to indicate your response as it applies to the past 7 days.

1. I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
Not at all                      ←————— Some-what                      —————→ Very much

2. My out-of-pocket medical expenses are more than I thought they would be.....

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
Not at all                      ←————— Some-what                      —————→ Very much

3. I worry about the financial problems I will have in the future as a result of my illness or treatment.....

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
Not at all                      ←————— Some-what                      —————→ Very much

4. I feel I have no choice about the amount of money I spend on care.....

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
Not at all                      ←————— Some-what                      —————→ Very much

5. I am frustrated that I cannot work or contribute as much as I usually

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
Not at all                      ←————— Some-what                      —————→ Very much

6. I am satisfied with my current financial situation.....

☐ 0                      ☐ 1                      ☐ 2                      ☐ 3                      ☐ 4  
Not at all                      ←————— Some-what                      —————→ Very much



4058406

7. I am able to meet my monthly expenses .....

☐ 0☐ 1☐ 2☐ 3☐ 4

Not at all



Some-what



Very much

8. I feel financially stressed.....

☐ 0☐ 1☐ 2☐ 3☐ 4

Not at all



Some-what



Very much

9. I am concerned about keeping my job and income, including work at home.....

☐ 0☐ 1☐ 2☐ 3☐ 4

Not at all



Some-what



Very much

10. My cancer or treatment has reduced my satisfaction with my present financial situation...

☐ 0☐ 1☐ 2☐ 3☐ 4

Not at all



Some-what



Very much

11. I feel in control of my financial situation.....

☐ 0☐ 1☐ 2☐ 3☐ 4

Not at all



Some-what



Very much

English (Universal)

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4058406

## NCCN Distress Thermometer and Problems List for Patients

**Instructions:** Please select the number between 0-10 that best describes how much distress you have been experiencing in the past week including today.

**Extreme distress**

**No distress**

A vertical thermometer-style scale with a bulb at the top and a base at the bottom. The scale is marked with numbers 0 through 10. To the left of each number is a small square box for selection. The top of the thermometer is labeled 'Extreme distress' and the bottom is labeled 'No distress'.

Distress Level	Selection Box
10	<input type="checkbox"/>
9	<input type="checkbox"/>
8	<input type="checkbox"/>
7	<input type="checkbox"/>
6	<input type="checkbox"/>
5	<input type="checkbox"/>
4	<input type="checkbox"/>
3	<input type="checkbox"/>
2	<input type="checkbox"/>
1	<input type="checkbox"/>
0	<input type="checkbox"/>



4058406

Please indicate if any of the following has been a problem for you in the past week including today.

**Yes No Practical Problems**

- ☐ ☐ Housing
- ☐ ☐ Insurance/financial
- ☐ ☐ Transportation
- ☐ ☐ Work/school
- ☐ ☐ Treatment decisions

**Yes No Family Problems**

- ☐ ☐ Dealing with children
- ☐ ☐ Dealing with partner
- ☐ ☐ Family health issues

**Yes No Emotional Problems**

- ☐ ☐ Depression
- ☐ ☐ Fears
- ☐ ☐ Nervousness
- ☐ ☐ Sadness
- ☐ ☐ Worry
- ☐ ☐ Loss of interest in usual activities
- ☐ ☐ Spiritual/religious concerns

**Yes No Physical Problems**

- ☐ ☐ Appearance
- ☐ ☐ Bathing/dressing
- ☐ ☐ Breathing
- ☐ ☐ Changes in urination
- ☐ ☐ Constipation
- ☐ ☐ Diarrhea
- ☐ ☐ Eating
- ☐ ☐ Fatigue
- ☐ ☐ Feelings swollen
- ☐ ☐ Fevers
- ☐ ☐ Getting around
- ☐ ☐ Indigestion
- ☐ ☐ Memory/concentration
- ☐ ☐ Mouth sores
- ☐ ☐ Nausea
- ☐ ☐ Nose dry/congested
- ☐ ☐ Pain
- ☐ ☐ Sexual
- ☐ ☐ Skin dry/itchy
- ☐ ☐ Sleep
- ☐ ☐ Substance abuse
- ☐ ☐ Tingling in hands/feet



4058406

**The Patient Health Questionnaire (PHQ-9)**

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the	Nearly every
1. Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling tired or having little energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Poor appetite or overeating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Trouble concentrating on things, such as reading the newspaper or watching television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Moving or speaking so slowly that other people could have noticed. Or the opposite--being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Thoughts that you would be better off dead or of hurting yourself in some way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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4058406

## Service Satisfaction Scale of Cancer Care for PT (SSS-PT)

Indicate the answer that best describes your feeling about each aspect of the services you have received. We are interested in your overall experience during the last year with care or therapy that you have received related to your cancer therapy or its side effects.

By "practitioner" we mean the one or more doctors, clinicians, etc., who have worked with you in your cancer-related care.

What is your overall feeling about the . . .

1. Effect of health care services in helping you deal with your cancer and maintain your well being?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

2. Professional knowledge and competence of your main cancer practitioner(s)?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

3. Ability of your main cancer practitioner(s) to listen and respond to your concerns or problems?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

4. Personal manner of the main cancer practitioner(s) seen?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

5. Waiting time between asking to be seen or treated and the appointment given?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

6. Waiting time when you come for an appointment?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		



4058406

**7. Availability of appointment times that fit your schedule?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

**8. Effect of cancer treatment in preventing cancer progression or recurrence?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

**9. How well your confidentiality and rights as an individual have been protected?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

**10. Quality of cancer care you have received?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

**11. Availability of information on how to get the most out of the cancer care and related services?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		

**12. Explanations of specific procedures and treatment approaches used?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied	Mixed			Completely Unsatisfied		



4058406

**13. Effect of services in helping relieve symptoms or reduce problems?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied ←			Mixed	→ Completely Unsatisfied		

**14. Thoroughness of the main cancer practitioner(s) you have seen?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied ←			Mixed	→ Completely Unsatisfied		

**15. Helpfulness of the information provided about your cancer and its treatment?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied ←			Mixed	→ Completely Unsatisfied		

**16. In an overall general sense, how satisfied are you with the cancer treatment you have received?**

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
Completely Satisfied ←			Mixed	→ Completely Unsatisfied		



4058406

## Income and Insurance

The next questions are about health insurance and health benefits because those things may affect the kind of care and treatment you get for your prostate cancer, or your health and well being overall. We will NOT contact your insurance company or tell them any of your answers.

### 1. Since our last interview, have you had any kind of health insurance or health benefits?

This includes: Medicare, Medicaid or other public assistance programs, military insurance or VA health benefits, private insurance (through a job or union, or that you paid for yourself), and any other kind of health insurance you might have.

☐ ALL of the time →

Skip to question #3

☐ PART of the time

Please tell us why you  
didn't have the insurance?

☐ NONE of the time →

☐ I don't know

### 2. Do you have any kind of health insurance or health benefits now?

☐ Yes

☐ No

☐ I don't know

### 3. Since our last interview, have you had any of the governmentsponsored health insurance plans?

☐ Yes

☐ No

### 4. Since our last interview, have you had any of the MILITARY or VA health insurance plans or benefits?

☐ Yes

☐ No



4058406

5. Since our last interview, did you have any OTHER kind of health insurance, besides government-sponsored and MILITARY or VA health insurance?

- ☐ Yes  
☐ No  
☐ I don't know

5a. If Yes, please tell us what kind?

6. Since our last interview, about how much money have you paid out of your own pocket for your medical care?

Include money for doctors, dentists, eye glasses, hearing aides, and medicine.  
Choose ONE answer.

- |  |  |
|--|--|
| <input type="checkbox"/> Less than \$500     | <input type="checkbox"/> \$12,000 - \$13,999 |
| <input type="checkbox"/> \$500 - \$999       | <input type="checkbox"/> \$14,000 - \$15,999 |
| <input type="checkbox"/> \$1,000 - \$1,999   | <input type="checkbox"/> \$16,000 - \$17,999 |
| <input type="checkbox"/> \$2,000 - \$2,999   | <input type="checkbox"/> \$18,000 - \$19,999 |
| <input type="checkbox"/> \$3,000 - \$4,999   | <input type="checkbox"/> \$20,000 - \$24,999 |
| <input type="checkbox"/> \$5,000 - \$6,999   | <input type="checkbox"/> \$25,000 - \$29,999 |
| <input type="checkbox"/> \$7,000 - \$9,999   | <input type="checkbox"/> \$30,000 or more    |
| <input type="checkbox"/> \$10,000 - \$11,999 | <input type="checkbox"/> I don't know        |

7. Overall, how HAPPY or UNHAPPY are you with your health insurance or health benefits?

*Choose a number from 1 to 5, where 1 means your are Very UNHAPPY and 5 means you are Very HAPPY.*

- ☐ 1 - Very Unhappy  
☐ 2  
☐ 3 - Not Unhappy or Happy  
☐ 4  
☐ 5 - Very Happy



4058406

The next questions are about your work and income. Your answers will help us understand how easy it is for you to get health care, and how prostate cancer has affected your life.

1. Which of the following best describes what you do now? Check ONE answer.

- ☐ Full time paid work
- ☐ Part time paid work
- ☐ Unemployed, looking for work
- ☐ Unemployed now, but have a job to return to
- ☐ Unable to work because of PROSTATE CANCER or treatment
- ☐ Unable to work because of OTHER HEALTH PROBLEMS
- ☐ Retired because of disability or illness due to PROSTATE CANCER or treatment
- ☐ Retired because of disability or illness due to OTHER HEALTH PROBLEMS
- ☐ Retired because of age
- ☐ Retired by choice
- ☐ I don't know
- ☐ Other (write your answer in the box)



4058406

**2. What is your current annual household income before you pay taxes?**

**Count all kinds of income including: government benefits like Social Security, as well as work or farm income, and include your own income and any other person's income that goes toward your household expenses. Choose ONE answer.**

- ☐ Less than \$10,400 a year.... (or less than \$867 a month)
- ☐ \$10,401 - \$14,000 a year.... (or \$868 - \$1,167 a month)
- ☐ \$14,001 - \$17,600 a year.... (or \$1,168 - \$1,467 a month)
- ☐ \$17,601 - \$21,200 a year.... (or \$1,468 - \$1,767 a month)
- ☐ \$21,201 - \$24,800 a year.... (or \$1,768 - \$2,067 a month)
- ☐ \$24,801 - \$28,400 a year.... (or \$2,068 - \$2,367 a month)
- ☐ \$28,401 - \$32,000 a year.... (or \$2,368 - \$2,667 a month)
- ☐ \$32,001 - \$35,600 a year.... (or \$2,668 - \$2,967 a month)
- ☐ \$35,601 - \$39,200 a year.... (or \$2,968 - \$3,267 a month)
- ☐ \$39,201 - \$45,000 a year .... (or \$3,268 - \$3,750 a month)
- ☐ \$45,001 - \$50,000 a year.... (or \$3,751 - \$4,167 a month)
- ☐ \$50,001 - \$55,000 a year.... (or \$4,168 - \$4,583 a month)
- ☐ \$55,001 - \$60,000 a year.... (or \$4,584 - \$5,000 a month)
- ☐ \$60,001 - \$70,000 a year.... (or \$5,001 - 5,833 a month)
- ☐ \$70,001 - \$80,000 a year.... (or \$5,834 - \$6,667 a month)
- ☐ \$80,001 or more a year.... (or \$6,668 or more a month)
- ☐ I don't know

**3. Including yourself, how many people are supported by this income? Choose ONE answer.**

- ☐ 1 person, I am the only person supported by this income
- ☐ 2 people
- ☐ 3 people
- ☐ 4 people
- ☐ 5 people
- ☐ 6 people
- ☐ 7 people
- ☐ 8 people
- ☐ 9 or more people
- ☐ I don't know



4058406

4. Sometimes people put off getting medical care that they need. Have you had to delay getting medical care, since you were diagnosed with prostate cancer?

- ☐ Yes
- ☐ No
- ☐ I don't know

4a. If YES, did you put off getting medical care for any of the following reasons?  
Check ALL that apply.

- ☐ I couldn't get through on the telephone
- ☐ I couldn't get an appointment soon enough
- ☐ I would have to wait too long at the doctor's office
- ☐ The clinic or doctor's office wasn't open when I could get there
- ☐ I couldn't take time off from work to go
- ☐ I didn't have any way to get there
- ☐ I couldn't afford the cost of transportation to get there
- ☐ I couldn't afford the cost of the visit
- ☐ I couldn't afford the medicine or treatments
- ☐ I don't know
- ☐ Other (write your answer in the box)



During the past 4 weeks, how much of the time were the following true for you? To answer, please choose a number from 1 to 5 for each, where 1 means **NONE** of the time and 5 means **ALL** of the time.

1. In the past four weeks, how much of the time have you accomplished less than you would like because of your physical health?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time                      ALL of the time

2. In the past four weeks, how much of the time were you limited in the kind of work or other activities you do because of your physical health?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time                      ALL of the time

3. In the past four weeks, how much of the time did you accomplish less than you would like because of emotional problems (such as feeling depressed or anxious)?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time                      ALL of the time

4. In the past four weeks, how much of the time did you do work or other activities less carefully than usual because of emotional problems?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time                      ALL of the time

5. In the past four weeks, how much of the time did you feel calm and peaceful?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time                      ALL of the time

6. In the past four weeks, how much of the time did you have a lot of energy?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time                      ALL of the time



4058406

7. In the past four weeks, how much of the time did you feel downhearted and depressed?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time      ←————→ ALL of the time

8. In the past four weeks, how much of the time did your physical health or emotional problems keep you from doing social activities, like visiting friends, relatives, etc.?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time      ←————→ ALL of the time

9. In the past four weeks, how much of the time did pain interfere with your normal work (including both work outside the home and housework)?

☐ 1                      ☐ 2                      ☐ 3                      ☐ 4                      ☐ 5  
NONE of the time      ←————→ ALL of the time



4058406

**10. Since our last interview, who has given you emotional support? Check ALL that apply.**

- ☐ Wife or Partner
- ☐ Daughter or Son
- ☐ Sister or Brother
- ☐ Mother or Father
- ☐ Other relative
- ☐ Friend(s)
- ☐ Neighbor(s)
- ☐ Co-worker(s)
- ☐ Church Member(s)
- ☐ Pastor, Priest, or other religious advisor
- ☐ God
- ☐ Club member(s)
- ☐ Prostate cancer support group
- ☐ Your doctor or doctors
- ☐ A counselor or therapist
- ☐ No one
- ☐ I don't know
- ☐ Other

**11. In general, how many close friends do you have? A "close friend" would be anyone you feel at ease with, can talk to about private things, and can call on for help. This could include your wife or other relatives, as well as friends who are not relatives.**

- ☐ None
- ☐ 1-3
- ☐ 4-5
- ☐ 6-7
- ☐ 8 or more

## **Smoking and Drinking**



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**1. Since our last interview, have you smoked cigarettes at least once a day at any time?**

- ☐ Yes
- ☐ No
- ☐ I don't know

**1a. If YES, about how many cigarettes did you smoke on a normal**

- ☐ 1-2
- ☐ 3-5
- ☐ 6-10
- ☐ 11-15
- ☐ 16-20
- ☐ 21-30 (1 - 1 1/2 packs a day)
- ☐ 31 - 40 (1 1/2 - 2 packs a day)
- ☐ More than 2 packs a day
- ☐ I don't know

**1b. If YES, do you smoke cigarettes at least once a day now?**

- ☐ Yes
- ☐ No
- ☐ I don't know

**2. Do you use any of the products listed below at least once a day now?**

- ☐ Chewing tobacco
- ☐ Cigars
- ☐ Snuff
- ☐ Pipe
- ☐ No



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**3. How often do you drink beer? Choose ONE answer.**

- ☐ NEVER ☐ 3 - 4 times a week  
☐ Once a month or less ☐ 5 - 6 times a week  
☐ 2 - 3 times a month ☐ Every day  
☐ 1 - 2 times a week

**3a. If you drink beer, how much do you usually drink? Choose ONE answer.**

- ☐ Less than 1 can or bottle (12 oz.)  
☐ 1 - 2 cans or bottles  
☐ 3 or more cans or bottles

**4. How often do you drink wine or wine coolers? Choose ONE answer.**

- ☐ NEVER ☐ 3 - 4 times a week  
☐ Once a month or less ☐ 5 - 6 times a week  
☐ 2 - 3 times a month ☐ Every day  
☐ 1 - 2 times a week

**4a. If you drink wine or wine coolers, how much do you usually drink?  
Choose ONE answer.**

- ☐ Less than 1 glass  
☐ 1 - 2 glasses  
☐ More than 2 glasses

**5. How often do you drink liquor or mixed drinks? Choose ONE answer.**

- ☐ NEVER ☐ 3 - 4 times a week  
☐ Once a month or less ☐ 5 - 6 times a week  
☐ 2 - 3 times a month ☐ Every day  
☐ 1 - 2 times a week

**5a. If you drink liquor or mixed drinks, how much do you usually drink?  
Choose ONE answer**

- ☐ Less than 1 shot of liquor  
☐ 1 - 3 shots of liquor  
☐ More than 3 shots of liquor



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**The next questions are about your usual exercise and physical activity.**  
**Please do NOT include work you did as part of your job.**

1. **In the past 12 months**, did you do any **LIGHT** exercise that didn't make you breathe any harder than usual at least once a week?

**NOTE:** "Light exercise" includes things like light yard work (gardening or pruning), light house work (dusting or vacuuming), playing golf with a cart, very easy bicycling or swimming, or light stretching.

- ☐ Yes  
☐ No  
☐ I don't know

- 1a. If YES, how many **days a week** did you do any kind of **LIGHT** exercise?  
Choose **ONE** answer?

- ☐ 1 - 2 days  
☐ 3 - 4 days  
☐ 5 - 7 days

- 1b. If YES, how many **hours a day** did you do any kind of **LIGHT** exercise?  
Choose **ONE** answer?

- ☐ Less than 1 hour  
☐ 1 - 2 hours  
☐ 3 hours or more

2. **In the past 12 months**, did you do **MODERATE** exercise that made you breathe somewhat harder than usual, at least once a week?

**NOTE:** "Moderate exercise" includes things like brisk walking or running, golfing without a cart or caddy, recreational swimming, moderate yard work (mowing with a power mower), doubles tennis, ballroom dancing, low impact or water aerobics, moderate housework (scrubbing floors or washing windows), or slow bicycling on level ground.

- ☐ Yes  
☐ No  
☐ I don't know



4058406

2a. If YES, how many days a week did you do any kind of MODERATE exercise?  
Choose ONE answer.

- ☐ 1 - 2 days
- ☐ 3 - 4 days
- ☐ 5 - 7 days

2b. If YES, how many minutes a day did you do any kind of MODERATE exercise?  
Choose ONE answer.

- ☐ 10 - 25 minutes
- ☐ 30 - 40 minutes
- ☐ 45 - 55 minutes
- ☐ 60 minutes or more

3. In the past 12 months, did you do VIGOROUS exercise that made you breathe much harder than usual, at least once a week?

**NOTE:** "Vigorous exercise" includes things like race-walking, jogging or running, aerobics, swimming laps, using a push mower, singles tennis, racquetball or squash, fast or steep hill bicycling, heavy housework, circuit training, stair machine, clogging or line dancing.

- ☐ Yes
- ☐ No
- ☐ I don't know

3a. If YES, how many days a week did you do any kind of VIGOROUS exercise?

- ☐ 1 - 2 days
- ☐ 3 - 4 days
- ☐ 5 - 7 days

3b. If YES, how many minutes a day did you do any kind of VIGOROUS exercise?

- ☐ 10 - 25 minutes
- ☐ 30 - 40 minutes
- ☐ 45 - 55 minutes
- ☐ 60 minutes or more



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**4. Do you have any other comments or suggestions?**

**“The PHQ-9 in the survey you have completed screens for depression, but please advise that this is not a diagnosis of your current mental health status. Please visit the National Alliance on Mental Illness website (<https://www.nami.org>) for more information on resources and services available or call the Suicide Prevention Lifeline at 1-800-273-8255 if you need immediate support.”**

**Thank you so much for completing this survey.**

**STATEMENT OF WORK: REVISED 07/31/2018**

**PROPOSED START DATE: 07/01/2017**

Site 1: Roswell Park Cancer  
Institute

Elm and Carlton Streets  
Buffalo, NY 14263

PI: James L. Mohler,  
MD

Site 2: University of North  
Carolina, Lineberger  
Comprehensive Cancer  
Center

CB#7294

Chapel Hill, NC 27599

Co-I: Jeannette T.  
Bensen, PhD

Site 3: Louisiana State University  
Health Sciences Center

School of Public Health 2020  
Gravier St.

New Orleans, LA 70112

Co-I: Edward S. Peters, DMD,  
SM, ScD

<b>Specific Aim 1</b> Locate and contact PCaP research subjects to update CaP status, CaP treatments received and comorbidities, repeat the QoL assessments performed at baseline and follow-up, and administer new surveys on financial burdens and stress and caregiver QoL and support	<b>Time line</b>	<b>Site 1</b>	<b>Site 2</b>	<b>Site 3</b>
<b>Major Task 1 Obtain follow-up from PCaP research subjects</b>	Months			
Subtask 1 Development: IRB approval at all sites, develop electronic and paper questionnaire forms, install and update patient and clinical medical records data tracking and collection system	0-12	Mohler	Bensen	Peters
Subtask 2 Locate, contact and re-consent	15-36			Peters
Subtask 3 Collect treatment, oncologic outcome information and identify treating MDs	15-36			Peters
Subtask 4 Administer questionnaires	15-36			Peters
Milestone(s) Achieved: 1/3 complete 2/3 complete All complete	22 29 36			
<b>Major Task 2 Obtain follow-up from caregiver/wife/partner/child(ren) of deceased PCaP research subjects</b>	Months			
Subtask 1 Locate, contact and re-consent	12-36			Peters
Subtask 2 Collect treatment, oncologic outcome information and identify treating MDs	12-36			Peters
Subtask 3 Administer questionnaires	12-36			Peters
Milestone(s) Achieved: 1/3 complete 2/3 complete All complete	20 28 36			
<b>Specific Aim 2</b> Collect data electronically, when possible, and locate and contact PCaP research subjects' treating physicians, when necessary, to update treatments received and oncologic outcome data				
<b>Major Task 1 Obtain follow-up electronically</b>				
Subtask 1 Conduct feasibility test on 20 NC research subjects and 20 LA research subjects	24-27		Bensen	Peters
Subtask 2 Collect electronic treatment and oncologic outcome data on NC research subjects	27-30		Bensen	
Subtask 3 Collect electronic treatment and oncologic outcome data on LA research subjects	27-30			Peters

<b>Major Task 2 Obtain follow-up from treating MDs</b>				
Subtask 1 Obtain follow-up from UNC in NC PCaP research subjects followed at UNC	27-36		Bensen	
Subtask 2 Obtain follow-up from NC MDs in NC PCaP research subjects not followed at UNC	27-36		Bensen	Peters
Subtask 3 Obtain follow-up from SEER for LA PCaP research subjects	27-36			Peters
Subtask 4 Obtain follow-up from LA MDs on LA PCaP research subjects without follow-up in SEER	27-36			Peters
Subtask 5 Abstract data using the PCaP Follow-up Form	27-36			Peters
Subtask 7 Enter data into PCaP Medical Records Abstraction Access Database	27-36			Peters
Milestone(s) Achieved: 1/3 complete 2/3 complete All complete	30 33 36			
<b>Major Task 3 Construct progression graphs</b>				
Subtask 1 Update progression graphs on NC PCaP research subjects	27-36	Mohler	Bensen	
Subtask 2 Construct progression graphs on LA PCaP research subjects	27-36	Mohler	Bensen	
Milestone(s) Achieved: 1/3 complete 2/3 complete All complete	30 33 36			
<b>Specific Aim 3 Obtain and link vital status data and cause of death in PCaP research subjects</b>				
<b>Major Task 1 Obtain vital statistics of NC PCaP research subjects</b>				
Subtask 1 Obtain vital statistics from NC Vital Records	1-12		Bensen	
<b>Major Task 2 Obtain vital statistics of LA PCaP research subjects</b>				
Subtask 1 Obtain vital statistics from LA State Tumor Registry in Year 1	1-12			Peters
<b>Major Task 3 Obtain vital statistics of NC and LA research subjects living outside NC and LA</b>				
Subtask 1 Obtain vital statistics form NDI of NCHS in year 1	1-12		Bensen	Peters
Subtask 2 Obtain vital status of any remaining PCaP research subjects by contacting their treating physicians and family members	12-18	Mohler	Bensen	Peters
Milestone(s) Achieved: >99% vital statistics available Obtain death status for any remaining cases	12 18			
<b>Specific Aim 4 Examine the role financial burden and stress have on CaP survival and QoL and whether this relationship was modified by race</b>				
<b>Major Task 1 Data management</b>				
Subtask 1 Maintain PCaP Data Sharing and Tracking System	0-48	Mohler	Bensen	Peters
Subtask 2 Create project-specific data repository	0-6	Mohler	Bensen	Peters
Subtask 3 Perform continuous data quality control	6-36	Mohler	Bensen	Peters
Subtask 4 Perform statistical analysis of quality-controlled data	36-48	Mohler	Bensen	Peters
<b>Major Task 2 Data Reporting</b>				
Subtask 1 Produce annual progress reports for PCaP	0-48	Mohler	Bensen	Peters

Subtask 2 Produce manuscripts	36-48	Mohler	Bensen	Peters
Milestone(s) Achieved: Produce PCRP Racial Disparity Program or PCORI proposal for intervention to address racial disparities in financial burden/stress and caregiver stress in families of men with CaP	42	Mohler	Bensen	Peters
Four manuscripts produced on 1) validation of Comprehensive Score for Financial Toxicity (COST); 2) financial burden/stress posed by CaP; 3) impact of death from CaP vs. death cured of CaP or with CaP; and 4) racial differences in financial burden/stress and caregiver stress in families of men with CaP	48	Mohler	Bensen	Peters