



# A Web-based Interactive Query System to Calculate Survival for Recently Diagnosed Cancer Patients

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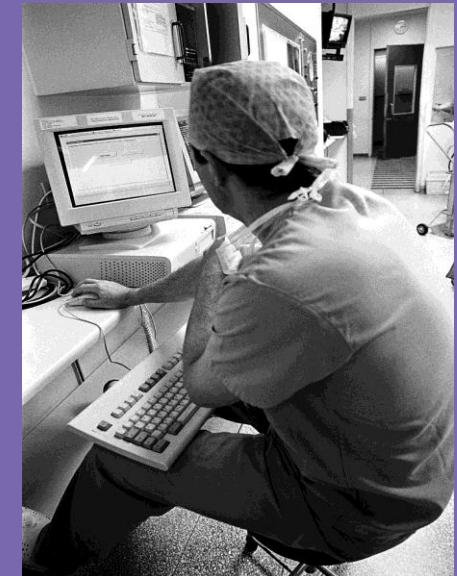
# Cancer Survival Query System (CSQS)

- Web-based interactive tool
- A physician's resource for calculating population-based cancer survival
- Adapts standard SEER survival stats
- Focuses on the probabilities of dying of cancer and other causes
- Designed to receive patient data input from physician



# Purpose of CSQS

- Determine the prognosis of a newly diagnosed patient
- Generate information on a cancer patient's survival
- Calculate survival in the presence of co-morbidities
- Improve clinicians ability to provide more accurate estimates of cancer prognoses



# Prototype Design

## ➤ SEER Data

- 13 SEER registries
- 20.3% of the US pop.

## ➤ Cancer Sites

- Colorectal, diagnosis yrs 1994-2005
- Prostate, diagnosis yrs 1995-2005

## ➤ AJCC Stage, 6<sup>th</sup> ed.

- with clinically relevant modifications for prostate
  - Localized inapparent or apparent, locally advanced, nodal disease, distant mets

# SEER Data

## ➤ Patient Information collected



- Demographics
- Primary tumor size
- Tumor site
- Tumor morphology
- Stage at diagnosis
- First course of treatment
- Survival
- Cause of death

## ➤ De-identified Data



# Standard SEER Survival vs CSQS

- Usual SEER survival statistics
  - Relative survival
    - Death from cancer in the absence of other causes of death
- CSQS presents the full survival picture
  - Chance of dying of cancer
  - Chance of dying of other causes
- CSQS presents individual survival to the extent it can be supported by SEER
  - Race, sex, stage, grade, subsite, histology, individual age, co-morbidity (using SEER-medicare linked data)

# CSQS Uniqueness

- Sophisticated method of incorporating co-morbidity
- Minimal statistical assumptions
  - Other tools use many assumptions to present information such as survival by treatment
- Serves as an aid when making treatment and/or other life decisions taking in account mortality from other causes
- Large database representative of the U.S.
  - Includes patients that may not be included in clinical trials
    - Elderly
    - Patients with many co-morbid conditions

# Cancer Survival Query System

A physician's resource for calculating population-based cancer survival



The Cancer Survival Query System (CSQS) uses the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) data, a premier source for cancer statistics in the U.S., to estimate survival and death rates from cancer and from other causes for a subpopulation that you define.

## Steps to use this site

- enter disease characteristics (designed to be completed by cancer specialist),
- select a specific age, race and gender,
- adjust for health status (for patients older than 65, you can do this by completing a checklist of co-morbid conditions),
- generate the results: survival from one to ten years , from cancer and other causes.

CSQS is not designed to predict outcomes by treatment choice, but can help the physician and patient decide on a course of treatment factoring in age and comorbid conditions. [More Info](#)

[Get Started: Colorectal Cancer](#)

[Get Started: Prostate Cancer](#)

If you are looking for other cancer survival tools or information for different cancer sites, see [Other Survival Tools / Nomograms](#) in our Additional Resources section.

## About this Site

This site presents statistics on the chance of dying of cancer and other causes. Typically, cancer survival figures filter out the influence of other causes of death and focus only on cancer deaths, which is useful for measuring progress in fighting cancer. But for an individual, it is more meaningful to simultaneously consider the chance of death from both cancer and other causes.

This tool is the result of ongoing research on how to make better use of the information collected by the SEER program. It provides estimates of survival for selected cancers that are specific to the characteristics of the tumor, age, race, gender and the overall health of a patient. It does not account for mode of detection, genomic profile, or treatment modality.

Ultimately, each case is unique. This tool aims to give the cancer specialist the best available population-based estimates for short- and long-term survival, as one of many pieces of information to weigh in helping patients and their families make difficult treatment and personal decisions.

[Read more »](#)

This tool was designed for use by cancer specialists. Someone without this background might not understand what to enter to generate accurate results, or how to interpret the results.

It is also not appropriate to use as a stand-alone tool. Discussion of cancer prognosis and treatment requires input from many sources of information.

If you are not a cancer specialist, please consult with a professional for help using this tool.

OK

# Cancer Survival Query System

A physician's resource for calculating population-based cancer survival



[Home](#) » Disease Characteristics

## Prostate Cancer: Disease Characteristics

Step 1 of 4

Staging Category:

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—Select—

—Select—

Pre-treatment clinical stage (for patients who have not made a treatment decision)

Pure clinical stage (for patients treated with modalities other than a radical prostatectomy)

Pathologic stage (for patients treated with a radical prostatectomy)

# Cancer Survival Query System

A physician's resource for calculating population-based cancer survival



[Home](#) » Disease Characteristics

## Prostate Cancer: Disease Characteristics

Step 2 of 4

**Staging Category:** Pre-treatment clinical stage (for patients who have not made a treatment decision)

**Clinical Stage:**

—Select—

-or-

[Calculate Clinical Stage...](#)

**Gleason's Score:**

—Select—

- [Localized Inapparent \(TURP diagnosis\) - T1a](#)
- [Localized Inapparent \(TURP diagnosis\) - T1b](#)
- [Localized Inapparent \(Elevated PSA\) - T1c](#)
- [Localized Apparent](#)
- [Locally Advanced - T3](#)
- [Locally Advanced - T4](#)
- [Nodal Disease - T1-T3](#)
- [Nodal Disease - T4](#)
- [Distant Metastases](#)

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# Cancer Survival Query System

A physician's resource for calculating population-based cancer survival



[Home](#) » [Disease Characteristics](#) » [Patient Demographics](#)

## Prostate Cancer: Patient Demographics

Step 3 of 4

**Age at Diagnosis:**

**Race:**  [More Info](#)

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# Cancer Survival Query System

A physician's resource for calculating population-based cancer survival



[Home](#) » [Disease Characteristics](#) » [Patient Demographics](#) » **Health Status**

## Prostate Cancer: Health Status

Step 4 of 4

Health Status Age Adjustment is the amount you would add or subtract from a person's age to account for good or poor health (prior to their diagnosis with cancer) relative to the average person of the same gender and racial group in the US population. [Example](#)

For patients age 66 to 90, we provide a calculator, based on Medicare claims data and Medicare claims data linked to SEER data with mortality follow-up, to compute the Health Status Age Adjustment based on the number and type of co-morbid conditions.

### Was the patient ever diagnosed with or treated for any of the following conditions?

AIDS	<input type="radio"/> Yes <input checked="" type="radio"/> No
Acute Myocardial Infarction (within 8 weeks before cancer diagnosis)	<input type="radio"/> Yes <input checked="" type="radio"/> No
Old Myocardial Infarction (more than 8 weeks before cancer diagnosis)	<input type="radio"/> Yes <input checked="" type="radio"/> No
Congestive Heart Failure	<input type="radio"/> Yes <input checked="" type="radio"/> No
Cerebrovascular Disease (includes late effects of CVD)	<input type="radio"/> Yes <input checked="" type="radio"/> No
Peripheral Vascular Disease	<input type="radio"/> Yes <input checked="" type="radio"/> No
Chronic Obstructive Pulmonary Disease	<input type="radio"/> Yes <input checked="" type="radio"/> No
Renal Disease (includes chronic glomerulonephritis, nephritis, nephropathy, chronic renal failure, unspecified renal failure, and disorders resulting from impaired renal function)	<input type="radio"/> Yes <input checked="" type="radio"/> No

<b>Rheumatologic Disease</b> (includes lupus erythematosus, systemic sclerosis, polymyositis, rheumatoid arthritis, rheumatoid lung, and polymyalgia rheumatica)	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>Ulcer Disease</b> (gastric, duodenal, peptic, and gastrojejunal ulcers)	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>Mild Liver Disease</b> (cirrhosis with or without mention of alcohol, biliary cirrhosis, chronic hepatitis)	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>Moderate-severe Liver Disease</b> (hepatic coma, portal hypertension, other sequelae of chronic liver disease)	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>Diabetes</b>	<input checked="" type="radio"/> Yes <input type="radio"/> No
<b>Diabetes With Sequelae</b> (renal, ophthalmic, or neurological manifestations)	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>Dementia</b> (senile and presenile dementias)	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>Paralysis</b> (hemiplegia, paraplegia)	<input type="radio"/> Yes <input checked="" type="radio"/> No

I do not have enough information to complete co-morbidities

**Age at Diagnosis:** 69

**Health Status Adjusted Age:** 73 (+4 years)

If you do not think the Health Status Adjusted Age adequately captures the condition of this patient (because of risk factors, other comorbidities not captured by the calculator, or the severity of comorbidities), or if there is insufficient information on co-morbidities to enter into the calculator, you can make a subjective assessment of the patient's Health Status Adjusted Age on the next page.

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## Prostate Cancer: Health Status (continued)

Step 4 of 4

**Age at Diagnosis:** 69

**Health Status Adjusted Age:** 73 (+4 years)

**Co-morbidities:** • Diabetes

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If there are other co-morbid conditions or risk factors that apply, you may make a subjective assessment of the patient's health status adjusted age. However, information from the calculator may yield more accurate results, since it is based on an analysis of Medicare claims data.

**What value would you like to use for the patient's health status adjusted age?**

- Age determined by calculator: **73 (+4 years)**
- Subjective assessment:

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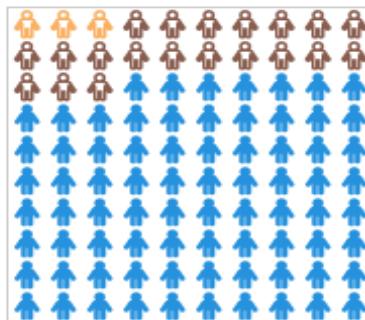
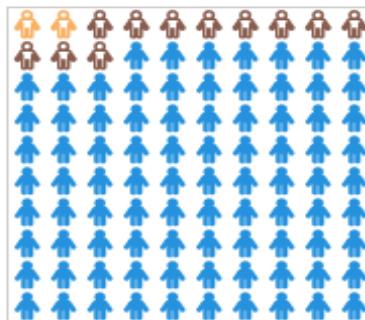
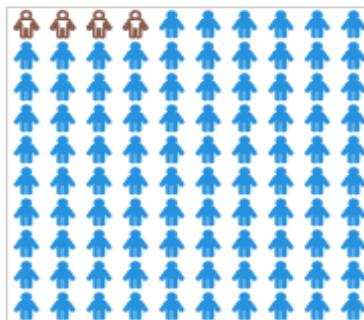
[Home](#) » [Disease Characteristics](#) » [Patient Demographics](#) » [Health Status](#) » [Summary of Results](#)

## Summary of Results

### Patient Prognosis

People Chart

Change Charts



1 year after diagnosis

3 years after diagnosis

5 years after diagnosis

Change Years

### It is estimated that by:

#### 1 year after diagnosis:

Approximately 0 out of 100 will die from their cancer,  
Approximately 4 out of 100 will die from other causes,  
Approximately 96 out of 100 will survive.

#### 3 years after diagnosis:

Approximately 2 out of 100 will die from their cancer,  
Approximately 11 out of 100 will die from other causes,  
Approximately 87 out of 100 will survive.

Orange figure = number who will likely die from their cancer

Grey figure = number who will likely die from other health related causes

Blue figure = number who will likely survive

[View Details](#)

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### Patient Characteristics

Health Status  
Adjusted Age: 73\*

[Modify Health Status](#)

Age at Diagnosis: 69

Race: Black

[Modify Patient Demographics](#)

Type: SC - Prostate Cancer

**Staging Category:** Pure clinical stage (for patients treated with modalities other than a radical prostatectomy)

**Clinical Stage:** Localized Inapparent (TURP diagnosis) - T1b

**Gleason's Score:** GS 2-7 Well or Moderately Differentiated - Grade I, II

[Modify Disease Characteristics](#)

# System Demonstration

- Focus Groups, Interviews and Usability Testing
  - Physicians
  - Advocates
  - Patients



# Physicians

## ➤ Recruitment

- 11 physicians
  - CoC invitation
  - Other

## ➤ Interview

- Background and experience with patients
- Experience with similar tools
- Opinion about CSQS



# Advocates

## ➤ Recruitment

- 9 advocates
  - NCI Office of Advocacy Relations
  - Prostate and colorectal cancer community
  - 7 cancer survivors



## ➤ Interview

- Background in patient advocacy
- Prognosis and survival conversations
- Opinion about CSQS

# Patients

## ➤ Recruitment

- 8 patients
  - Diagnosed with cancer within the past two to seven yrs



## ➤ Focus Group

- Kinds of information and questions patients want
- Impressions of CSQS

# Findings - Survival Data

## ➤ Physicians

- Many used online tools for prognosis data
- Most felt online tools don't handle co-morbidity well and don't take into account how treatment affects prognosis
- Data must be presented with proper sensitivity

## ➤ Advocates

- Survival data should be available to patient community
  - There is a risk of patients misinterpreting treatment statistics
- A print-out of their survival output is good for dialogue with their physician.

# Findings - Survival Data

## ➤ Patients

- At time of diagnosis, the focus is on treatment options
- Questions about survival come later
- Most were interested in getting survival information especially if they had previous experience with the disease, but from their physician

# Findings - Co-morbidity

## ➤ Physicians

- Would like an online tool where one can enter co-morbidity to generate prognosis
- Co-morbidity is particularly an issue with older populations

## ➤ Advocates

- Most said they could not imagine a newly diagnosed patient thinking about anything other than cancer; but maybe they should

# Findings - Co-morbidity

## ➤ Patients

- Initially, other health concerns took a back seat to dealing with cancer
- CSQS brought awareness to the importance of addressing co-morbidities as well as the cancer

# Findings – Sources Used

## ➤ Physicians

- Online calculators, i.e., Adjuvant, CaP
- Textbooks
- Latest literature
- Adjuvant

## ➤ Advocates/Patients

- Physician
- Online articles
- websites

# Reactions to CSQS

- CSQS would be beneficial if it offers something that other tools don't
  - More detailed input and output
  - A great co-morbidity model
- It is good that CSQS is based on SEER data for it contains longitudinal data
- The sheer volume of patients included in the SEER database would make it more powerful
- There is concern about hopelessness and psychological impact by patients who see grim statistics

# Resources List

- Doctor
- Patient
- Adjuvant
- PDQ

# Resources



National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

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[Home](#) » Physician Resources

### Physician Resources

#### • Other Survival Tools / Nomograms

- [Adjuvant! Online](#) - "The purpose of Adjuvant! is to help health professionals and patients with early cancer discuss the risks and benefits of getting additional therapy (adjuvant therapy: usually chemotherapy, hormone therapy, or both) after surgery."
- [Sloan-Kettering: Prediction Tools](#) - Nomograms for selected urologic cancers and other cancers including prostate, bladder, breast, colorectal, skin (melanoma), gastric, lung, renal cell carcinoma, sarcoma, and pancreas.
- [Kattan Nomograms](#) -

#### • Treatment

- [Adjuvant! Online](#) - "The purpose of Adjuvant! is to help health professionals and patients with early cancer discuss the risks and benefits of getting additional therapy (adjuvant therapy: usually chemotherapy, hormone therapy, or both) after surgery."
- [American Society of Clinical Oncology \(ASCO\) Practice Guidelines](#) - "ASCO is in a unique position to meet the distinct needs and challenges faced by oncologists practicing in the community. ASCO develops numerous programs, tools, and resources specifically tailored to the needs of practicing oncologists in the promotion of high-quality cancer care."
- [National Comprehensive Cancer Network \(NCCN\) Clinical Practice Guidelines](#) - "The NCCN Clinical Practice Guidelines in Oncology™—the recognized standard for clinical policy

### Additional Resources

[Physician Resources](#)

[Patient Resources](#)

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# Conclusion

- CSQS will assist clinicians in calibrating their intuition about survival for individuals
  - Provide more accurate estimates of cancer prognoses
- Physicians will better integrate other cause mortality into making treatment and other life decisions
- Physician communication is important in providing sensitive information



# Next Phase

- Collaboration/Patient care research

# Thank You!

