Giving men with prostate cancer the data to make better decisions
1 in 6 men in the U.S. will get prostate cancer in their lifetime.

Today, 3 million men in the U.S. have prostate cancer.
Treatment Recommendations, today

Prostate Cancer Treatment
Possible Side Effects

Higher Risk | Lower Risk

Incontinence | Impotence | Surgical Risk | Chance of Recurrence

Traditional Surgery
Minimally Invasive/Robotic Surgery
External Beam Radiation/IMRT
Brachytherapy
Cryosurgery
Hormone Therapy
Active Surveillance
Treatment Recommendations, today

### Prostate Cancer Treatment

#### Possible Side Effects

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Higher Risk | Lower Risk
Current State:
Generic advice

Young
Aggressive disease
Family History
MPOWER PROSTATE CANCER REGISTRY

Mpower: Empowering men
Our online community is for men who have been diagnosed with prostate cancer and their families and friends.

Ask A Doctor
Our experts have answered the questions they are most often asked about prostate cancer symptoms, diagnosis, prevention, screening, nutrition and treatment.

Sign Up Today
Soon we will be conducting a survey for men who have been diagnosed with prostate cancer. We need your input.

Mpower

ABOUT US
Empowering Men
Working to better understand the experiences of men throughout the Northwest who are diagnosed with prostate cancer and provide information enabling people to make the best decisions possible.

INFORMATION DATABASE
Our Registry
Our registry will capture information from men diagnosed with prostate cancer that will expand our knowledge about risk prediction, diagnostic trends, treatment patterns, outcomes and quality of life.

FACTS / STUDIES
Prostate Cancer
In 2013, nearly 6,000 men were affected by prostate cancer. Read the most current prostate cancer statistics and find links to current clinical trials.
Current State: Generic advice
Future State:
Personalized advice
Data Driven

Young
Aggressive disease
Family History
Better data, better decisions

<table>
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<th>Category</th>
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<td>Big Problem</td>
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<td>3.7</td>
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<tr>
<td>Moderate Problem</td>
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<td>3.5</td>
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<td>Small Problem</td>
<td>3</td>
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<td>2.4</td>
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<td>Very Small Problem</td>
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Patients like you vs All Mpower patients
Californian Sentenced to Prison for HIPAA Violation

Posted By Chris Dimick on Apr 29, 2010

[Editor's note, August 9, 2010: Huping Zhou was the first person in the nation to receive jail time for a misdemeanor HIPAA offense—for accessing confidential records without a valid reason or authorization but not profiting from it through the sale or use of the information.]

A former UCLA Health System employee became the first person in the nation to receive jail time for profiting from the sale or use of the information.

Huping Zhou, 47, of Los Angeles, was sentenced to four months in federal prison Monday for stealing and selling confidential information from patients, according to the U.S. Attorney.

In 2009, Zhou was working as a data entry clerk at the UCLA Health System. He's accused of stealing and selling the personal and medical records of high-profile celebrities, according to the U.S. Attorney.

Over the course of one year, Zhou also sold the records of Tom Hanks, Tom Cruise and other Hollywood stars, according to the U.S. Attorney. Zhou sold the private and medical records of these actors to undercover agents...

UCLA Health System pays $865G to settle HIPAA violation charges

July 8, 2011 | By Ken Terry

UCLA Health System has agreed to pay a fine of $865,000 and to develop a correction action plan to settle potential HIPAA privacy violations involving improper disclosures of medical records at its three hospitals, the federal Office of Civil Rights (OCR) reports.

OCR launched the investigation in 2009, following complaints by two unnamed celebrities that their medical records had been compromised. The government probe revealed that from 2005 to 2008, "unauthorized employees repeatedly looked at the electronic protected health information of numerous other UCLAHS patients," according to an OCR press release.

The Los Angeles Times reports that violations allegedly occurred at all three UCLAHS hospitals: Ronald Reagan UCLA Medical Center, Santa Monica UCLA Medical Center, and Orthopaedic Hospital and Resnick Neuropsychiatric Hospital, which are regarded as a single unit.
1. **Responses to the consent form are stored securely**  
   (Protected Health Information)

2. Responses to the survey are stored securely  
   (Protected Health Information)

3. Responses to the consent form and to the survey can be linked by the M POWER team
LabKey Architecture

Public Facing Server

Private Server: In Hutch Firewall

Consent

Consent Identifiers: Name, Date of Birth

NAME:* Bruce Lee

EMAIL ADDRESS:* Bruce.Lee@gmail.com

DATE OF BIRTH:* 12/1/1956
NAME:* Bruce Lee  
EMAIL ADDRESS:* Bruce.Lee@gmail.com  
DATE OF BIRTH:* 12/1/1956

Consent Identifiers: Name, Date of Birth  
Secure Token = 45678
Treatment

Be sure you complete all sections before you submit!

Who was the primary clinician for your treatment for your prostate cancer?

- Doctor (Medical Oncologist)
- Doctor (Urologist)
- Doctor (Surgeon)
- Doctor (Primary Care)
- Doctor (Radiation Oncologist)
- Nurse or other health professional

What treatment(s) did you have for your prostate cancer?
Select all that apply.

- Active surveillance
- Surgery
- Radical prostatectomy (prostate gland removal)
  - Approximate date of treatment: 02/09/1993
  - Type of surgery:
    - Minimally invasive technique using robotic surgery
    - Open technique (Surgery incision is often 4-5 inches long)
    - Do not know the type of operation

Overall, how satisfied are you with the treatment(s) you received for your prostate cancer?
Quality of Life

Be sure you complete all sections before you submit!

In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

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

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

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

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

- Hot flashes:
- Breast tenderness/enlargement:
- Loss of Body Hair:
- Feeling depressed:
- Lack of energy:
- Changes in body weight:
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Requirements

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LabKey Architecture

Private Server: In Hutch Firewall

Consent Identifiers: Name, Date of Birth
=45678

Medical Records, Labs, Fitbit

Survey Answers
=45678
M POWER: How will we use the data?

Patient Benefits

• Decision making support

• Care engagement and education

• Learn about upcoming research and prevention strategies

• Connect with resources
How much do your side effects from treatment bother you?

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Patients like you: All Mpower patients
M POWER: How will we use the data?

Patient Benefits
- Decision making support
- Care engagement and education
- Learn about upcoming research and prevention strategies
- Connect with resources

Clinicians & Researchers
- Help researchers and clinicians better understand the trends in the community
- Design research interventions
Interventions to improve outcomes
**M POWER:** How will we use the data?

**Patient Benefits**
- Decision making support
- Care engagement and education
- Learn about upcoming research and prevention strategies
- Connect with resources

**Clinicians & Researchers**
- Help researchers and clinicians better understand the trends in the community
- Design research interventions

**Prostate Cancer Advocacy**
- Increase public awareness and visibility of Prostate Cancer

© Fred Hutchinson Cancer Research Center
Future Directions

• We are launching this month

• Thank you Karl and Jessi, my awesome LabKey Team
Thank you!

Please contact me with any questions
nklemfus@seattlecca.org
MpowerNW.org
To secure the private server from the public server the following steps will be taken:

1. The credentials used by the public server to access the private server will have no access (read, write, delete, etc.) to any of the folders.

2. A custom security permission will be created programmatically and introduced into the LabKey server through the MPower custom module.

3. New API actions will be created to:
   - a. post initial identifying information and return a security token
   - b. save survey answers
   - c. return aggregate information

4. The new actions created in #3 will require the security permission from #2

5. The credentials from #1 will only have the new security permission.