

Mpower NW PROJECT

*Giving men with
prostate cancer
the data
to make better
decisions*

UW Medicine



FRED HUTCH
CURES START HERE™

MPOWER PROSTATE CANCER REGISTRY

+ Share



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.



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.

1 IN 6 MEN IN THE U.S. WILL
GET PROSTATE CANCER
IN THEIR LIFETIME




238,000+

MEN DIAGNOSED WITH PROSTATE CANCER
IN THE UNITED STATE, 2013

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

Higher Risk      Lower Risk

	Incontinence	Impotence	Surgical Risk	Chance of Recurrence
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External Beam Radiation/IMRT				
Brachytherapy				
Cryosurgery				
Hormone Therapy				
Active Surveillance				

Current State: Generic advice



Young
Aggressive disease
Family History



Mpower: Empowering men

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



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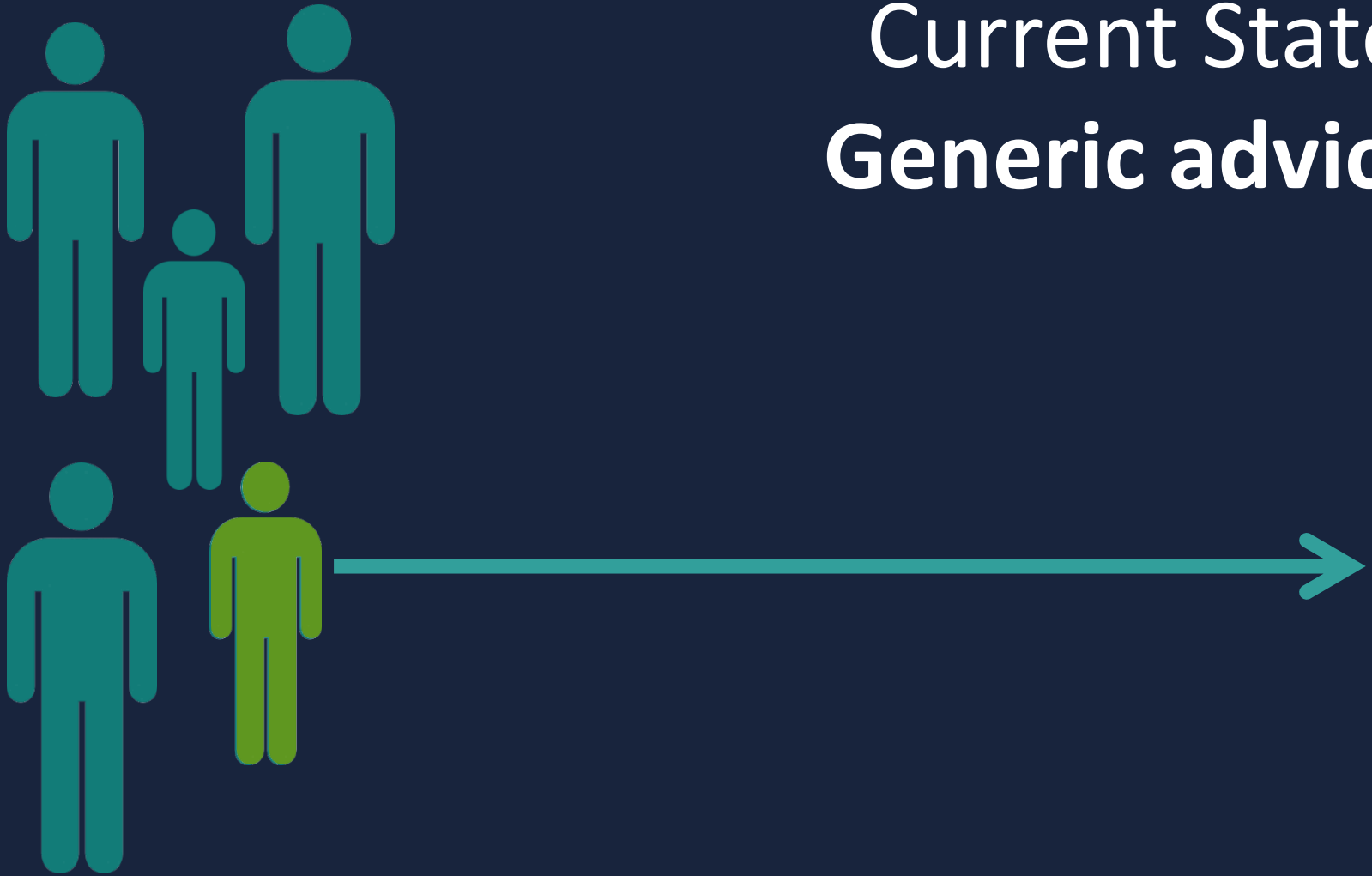


FACTS / STUDIES

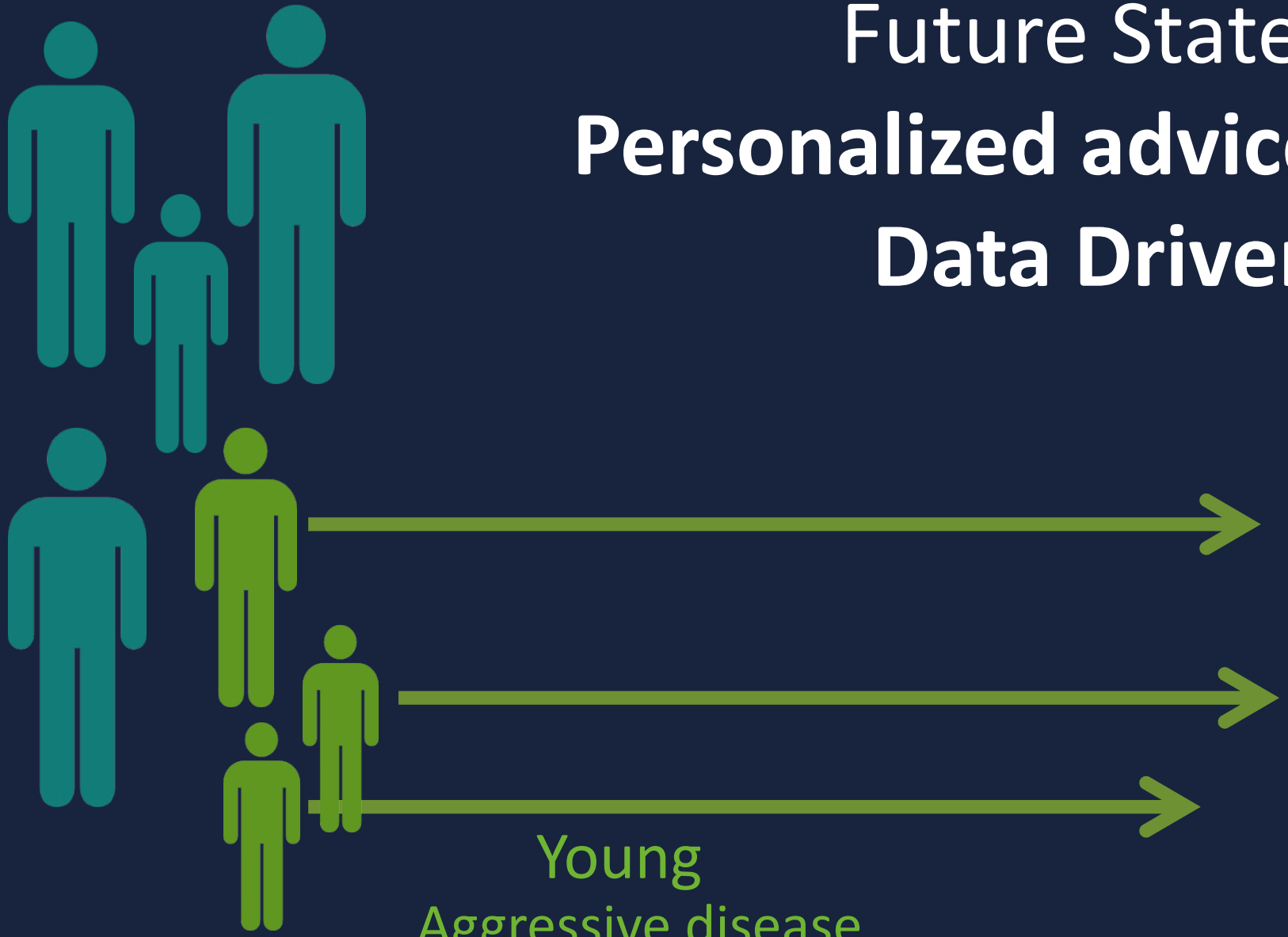
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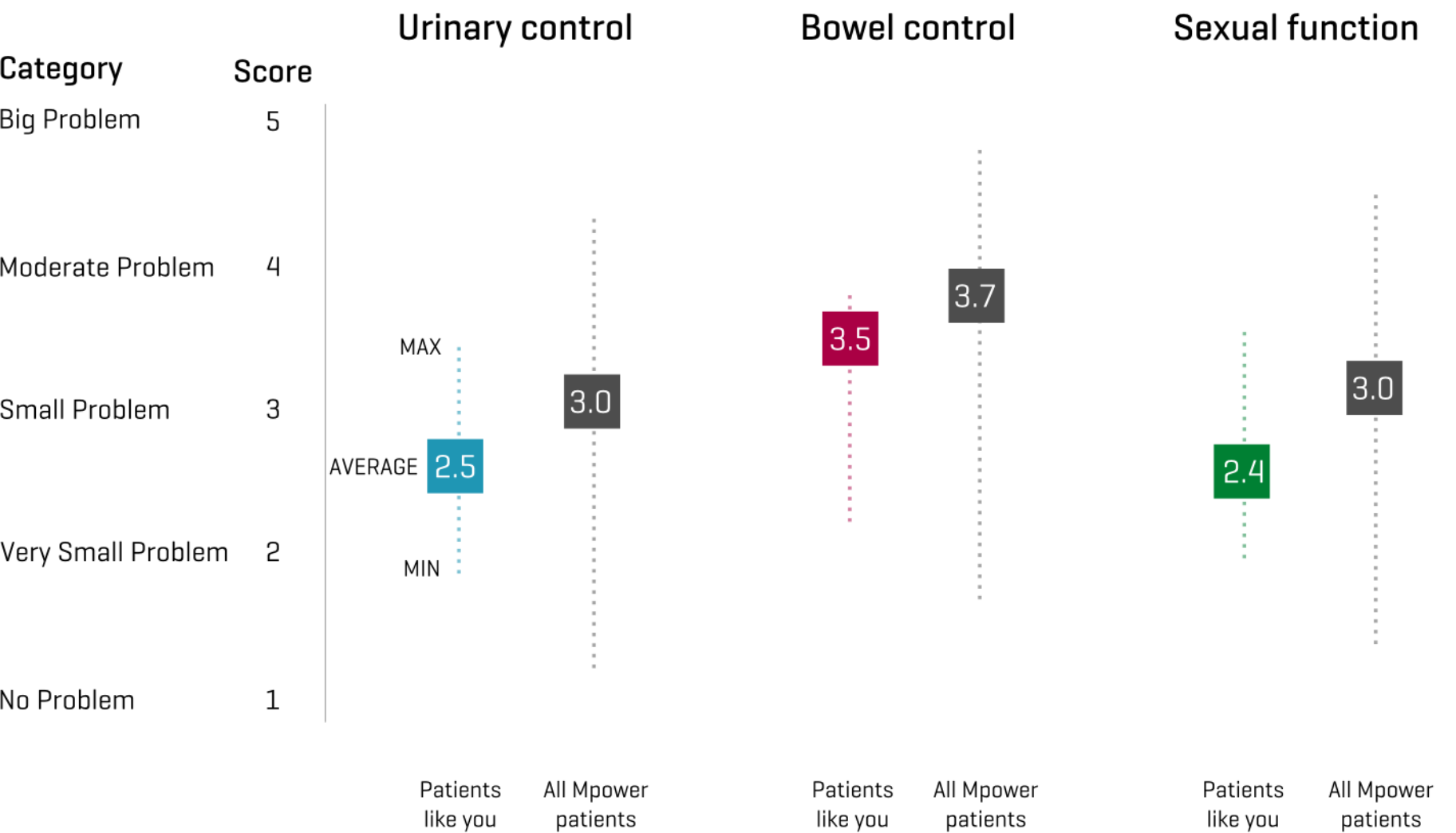
Current State: Generic advice



Future State: Personalized advice Data Driven



Better data, better decisions



Clinical Data

Treatment Outcomes

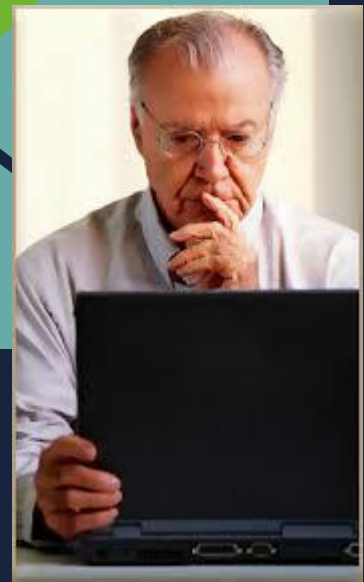
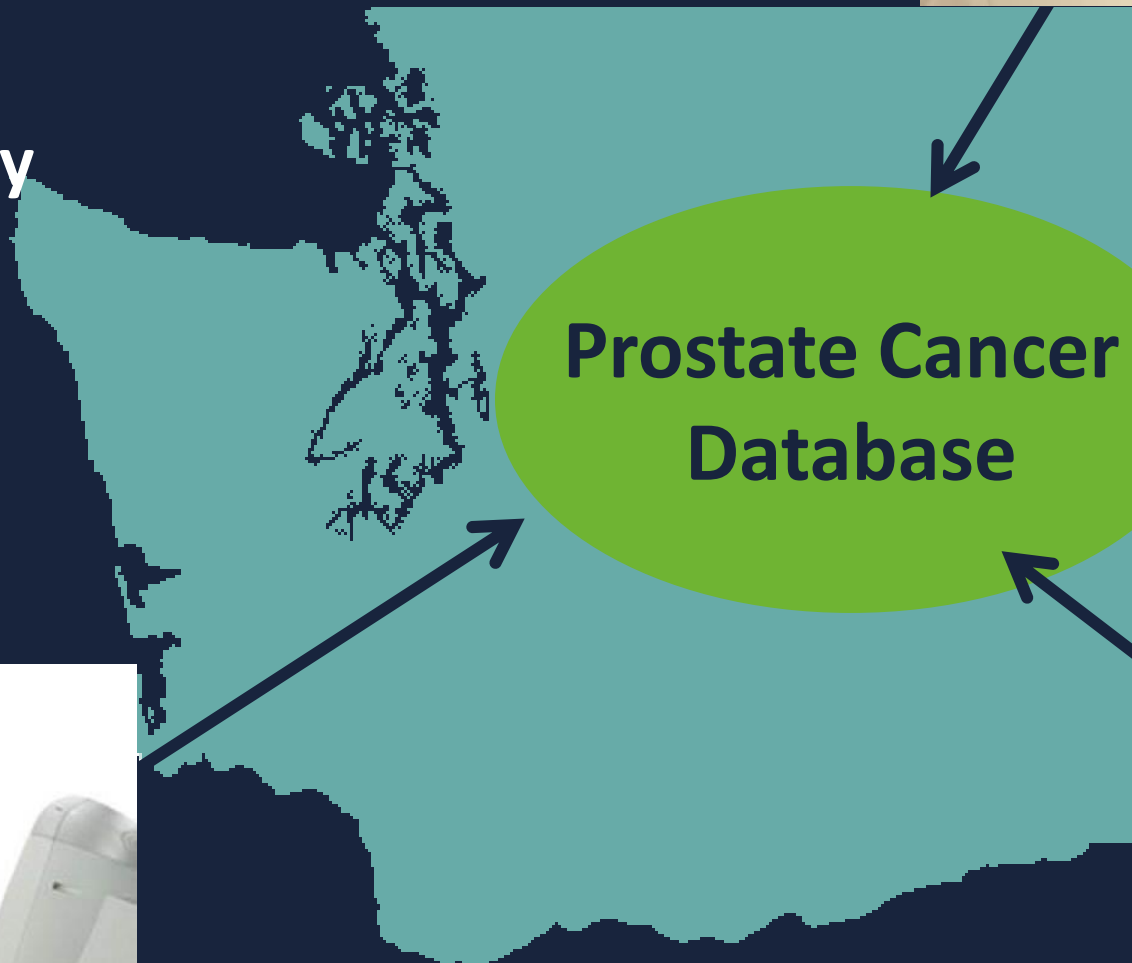
Quality of Life

Side Effects

Lifestyle

Family History

CONFIDENTIAL



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 violating HIPAA.

Huping Zhou, 47, of Los Angeles, was sentenced to four months in jail for four misdemeanor counts of accessing and releasing confidential medical records of patients and high-profile celebrities, according to the U.S. Attorney in Los Angeles. Zhou also pleaded guilty to one count of conspiracy to violate HIPAA.

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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.



Requirements

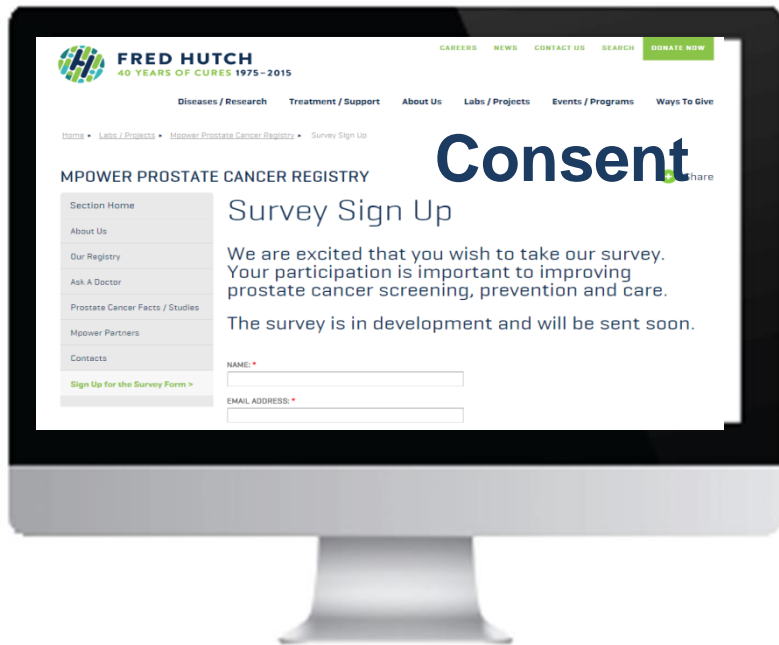


LabKey Software™
PARTNERS IN SCIENCE

1. **Responses to the consent form are stored securely**
(Protected Health Information)
2. Responses to the survey are stored securely
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3. Responses to the consent form and to the survey can
be linked by the M POWER team

LabKey Architecture

Public Facing Server

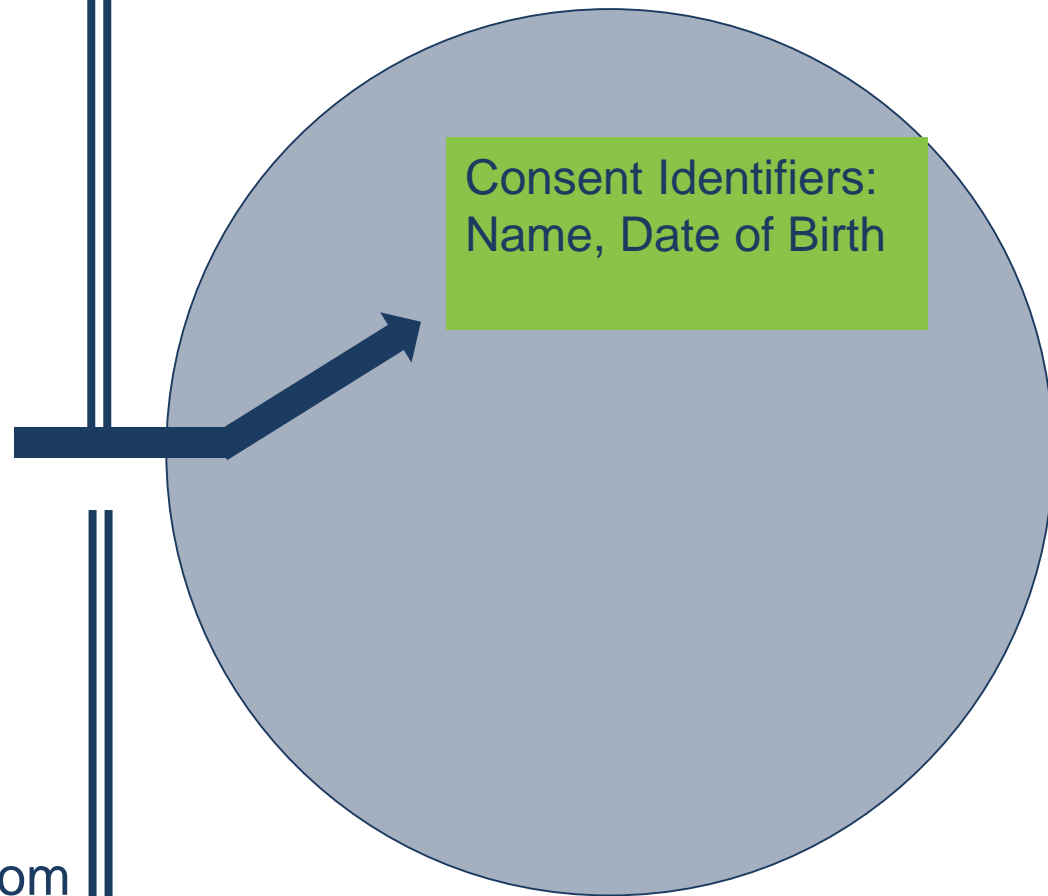


NAME:* Bruce Lee

EMAIL ADDRESS:* Bruce.Lee@gmail.com

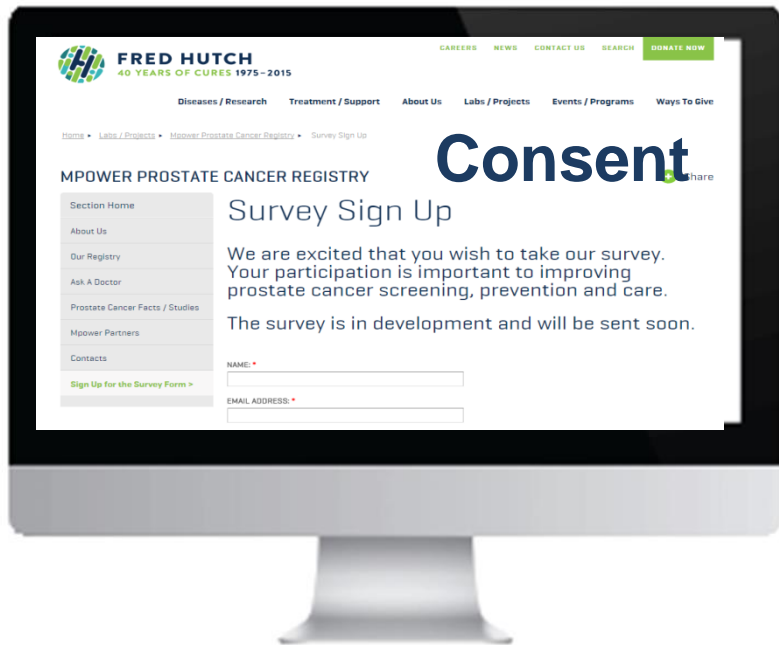
DATE OF BIRTH:* 12/1/1956

Private Server: In Hutch Firewall



LabKey Architecture

Public Facing Server

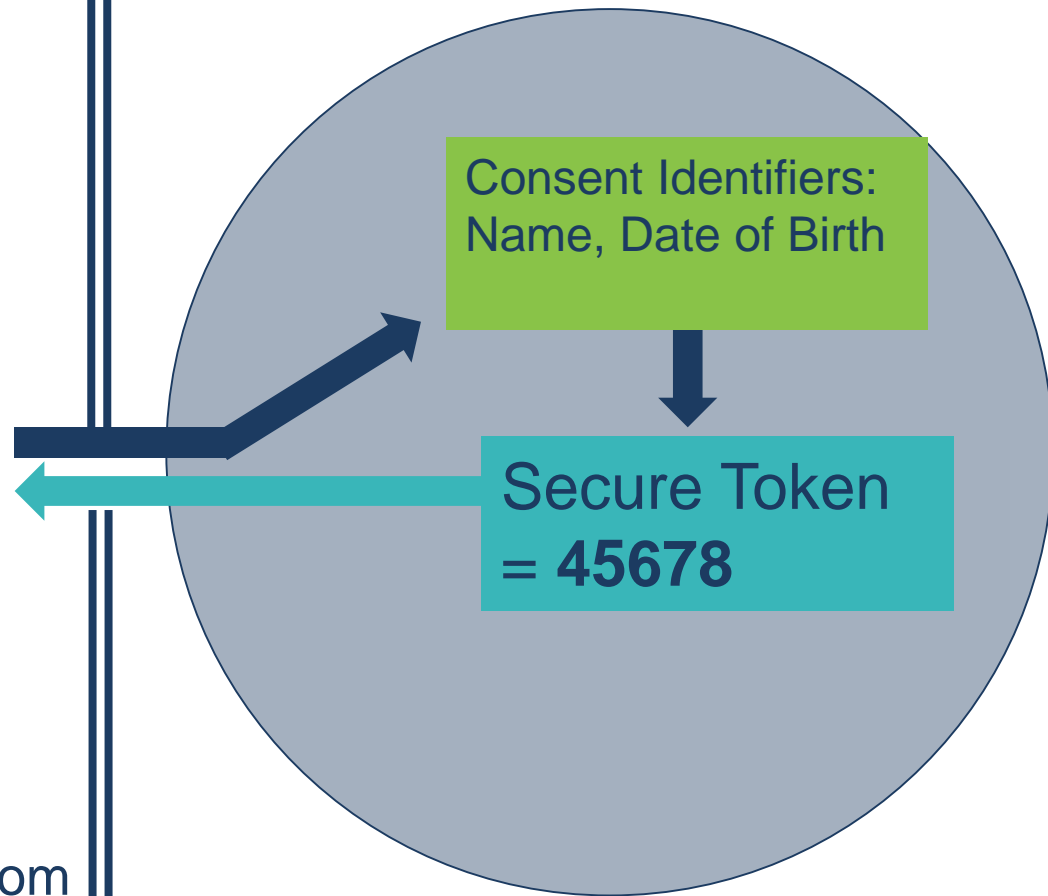


NAME:* Bruce Lee

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M POWER Prostate Cancer Online Survey

Powered by LabKey

Start

Patient Characteristics

Clinical Diagnosis

Family History of Prostate Cancer

Treatment

Quality of Life

Lifestyle

Save / Submit

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:

- Select
- Minimally invasive technique using robotic surgery
- Open technique (Surgery incision is often 4-5 inches long)
- Do not know the type of operation

☐ Orchiectomy (testis removal)

☐ Other surgery

☐ Cryotherapy/cryosurgery (freezing prostate)

☐ Radiation

☐ Medical Treatment

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

Select

PREVIOUS NEXT

M POWER Prostate Cancer Online Survey

- Start
- Patient Characteristics
- Clinical Diagnosis
- Family History of Prostate Cancer
- Treatment

Quality of Life

- Lifestyle
- Save / Submit

Quality of Life

Be sure you complete all sections before you submit!

In general, would you say your health is:

Select

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?

Select

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

Hot flashes:

Select

Breast tenderness/enlargement:

Select

Loss of Body Hair:

Select

Feeling depressed:

Select

Lack of energy:

Select

Changes in body weight:

Select

Requirements

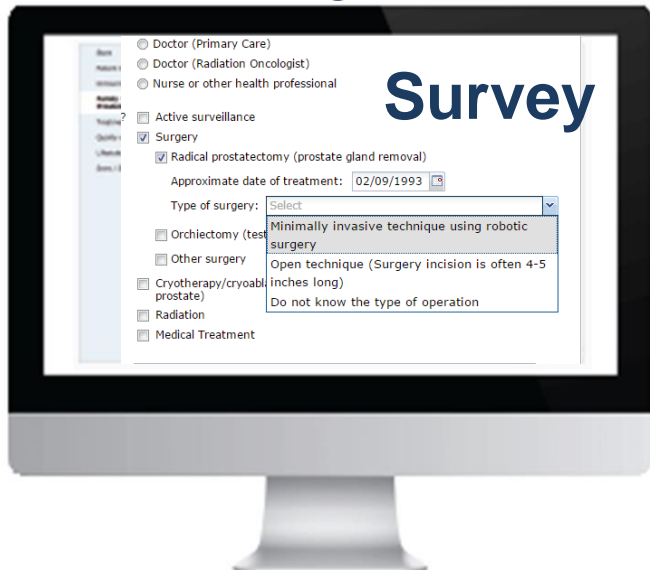


LabKey Software™
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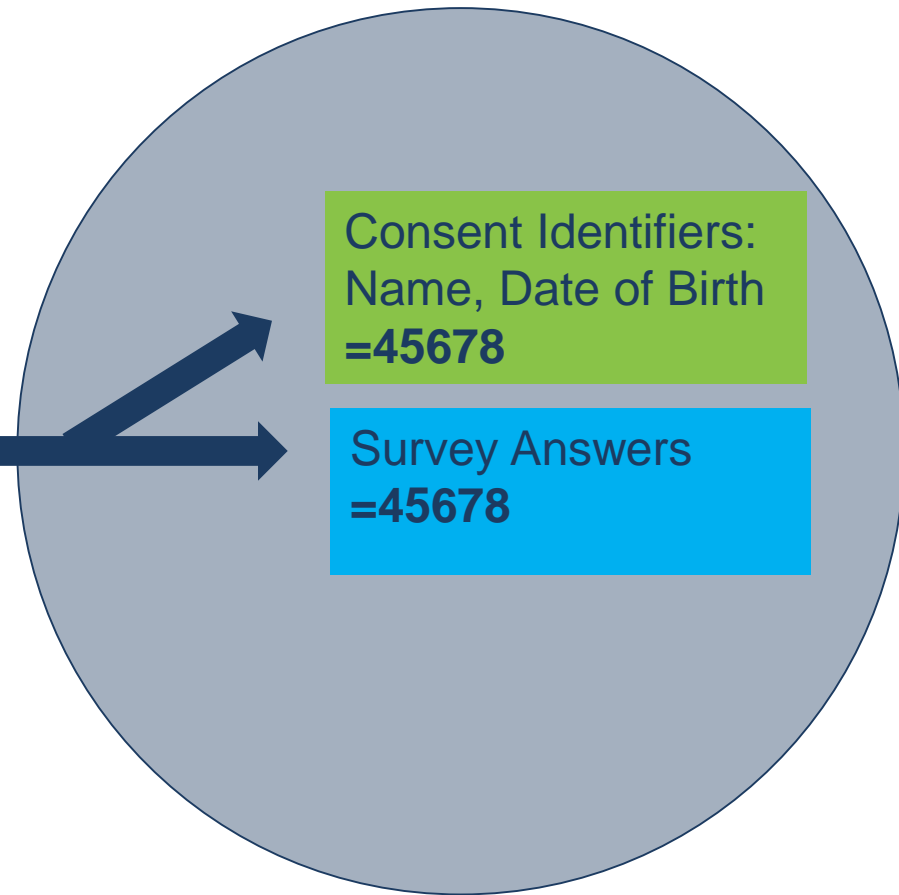
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LabKey Architecture

Public Facing Server



Private Server: In Hutch Firewall

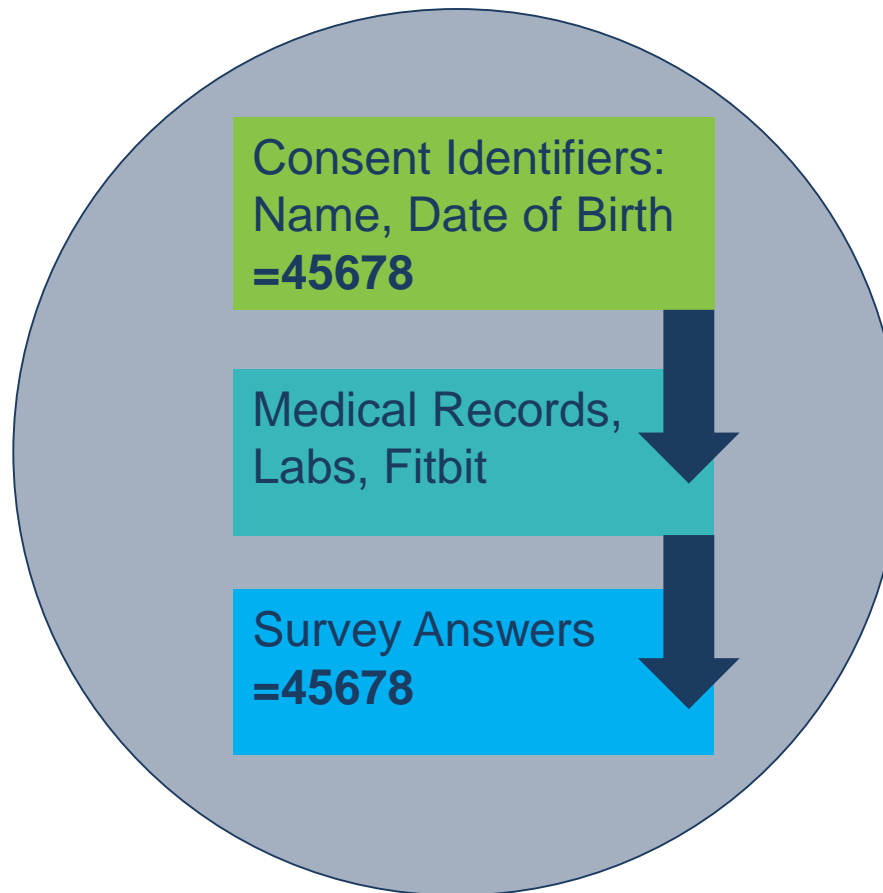




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LabKey Architecture

Private Server: In Hutch Firewall



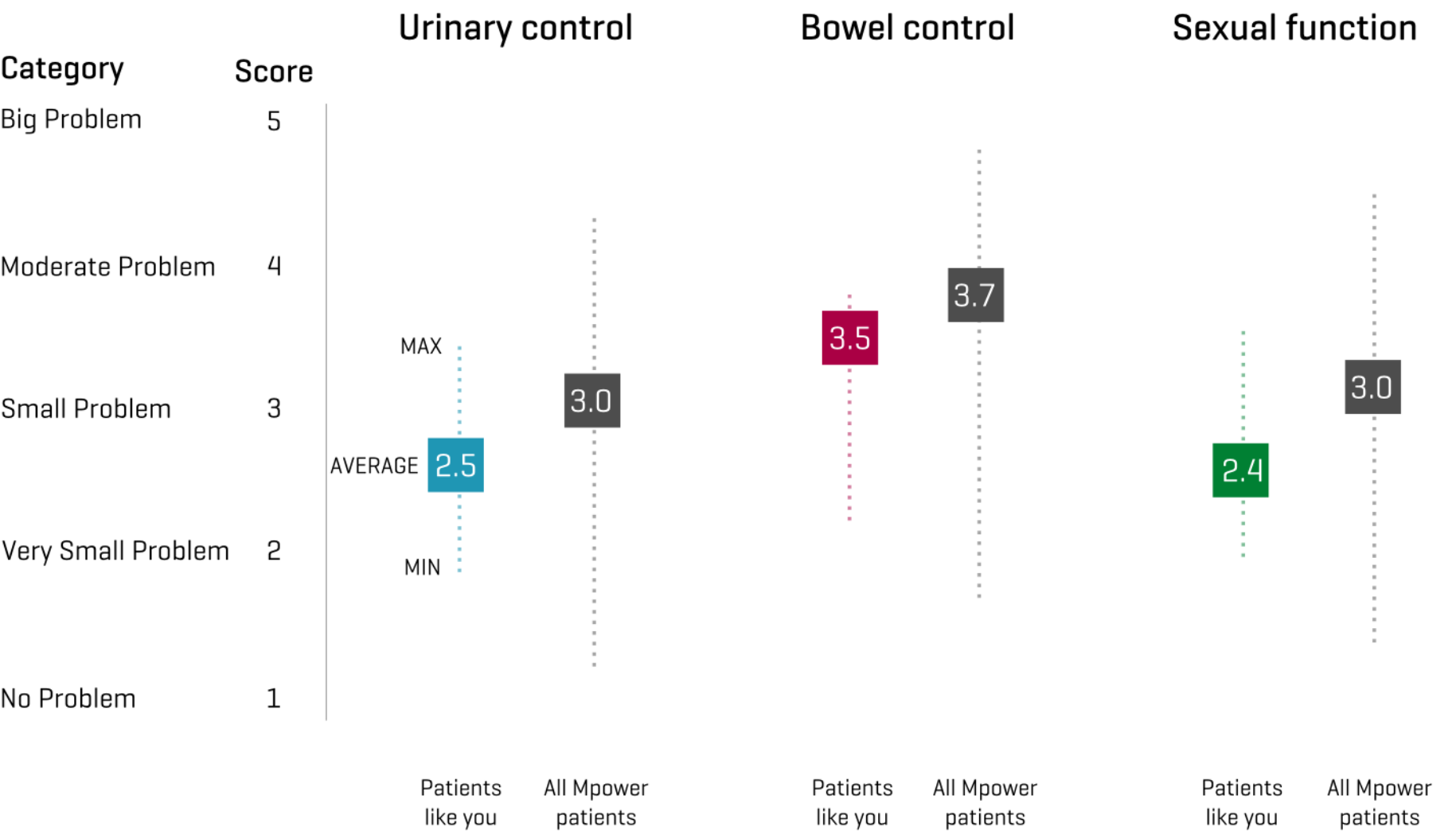
M POWER: How will we use the data?



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?



M POWER: How will we use the data?



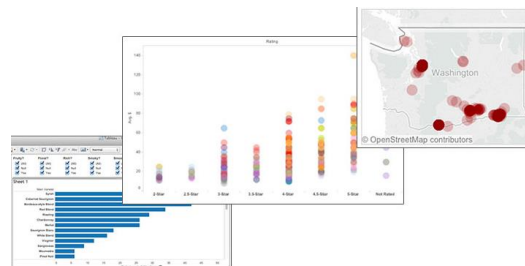
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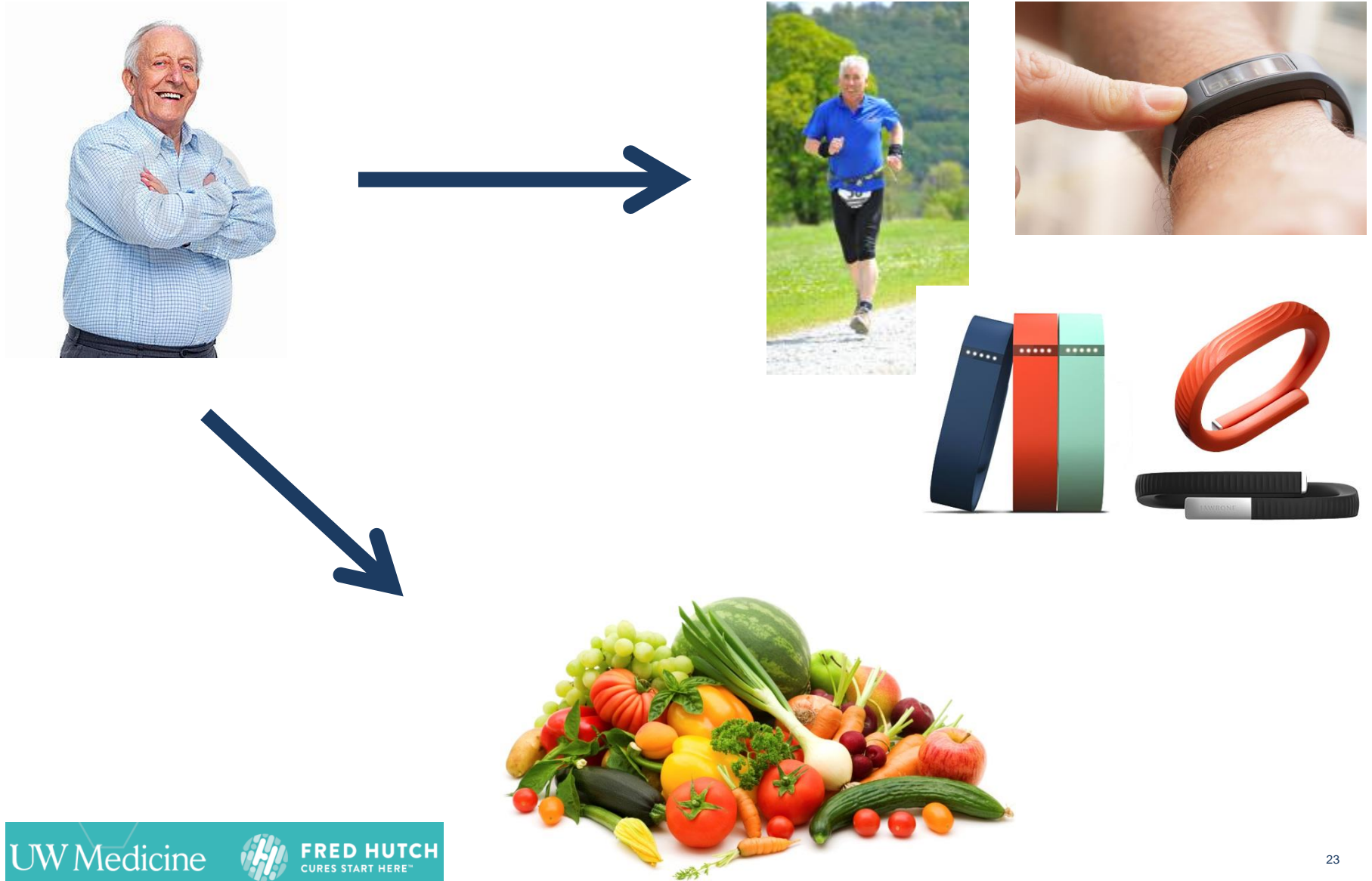


Clinicians & Researchers

- 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?



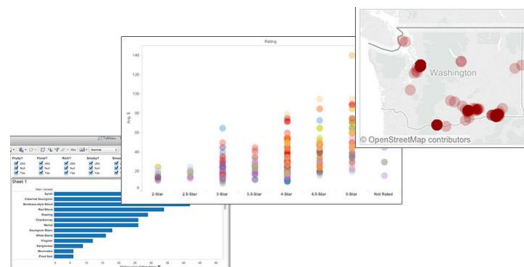
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Prostate Cancer Advocacy

- Increase public awareness and visibility of Prostate Cancer



Future Directions

- We are launching this month
- Thank you **Karl and Jessi**, my awesome LabKey

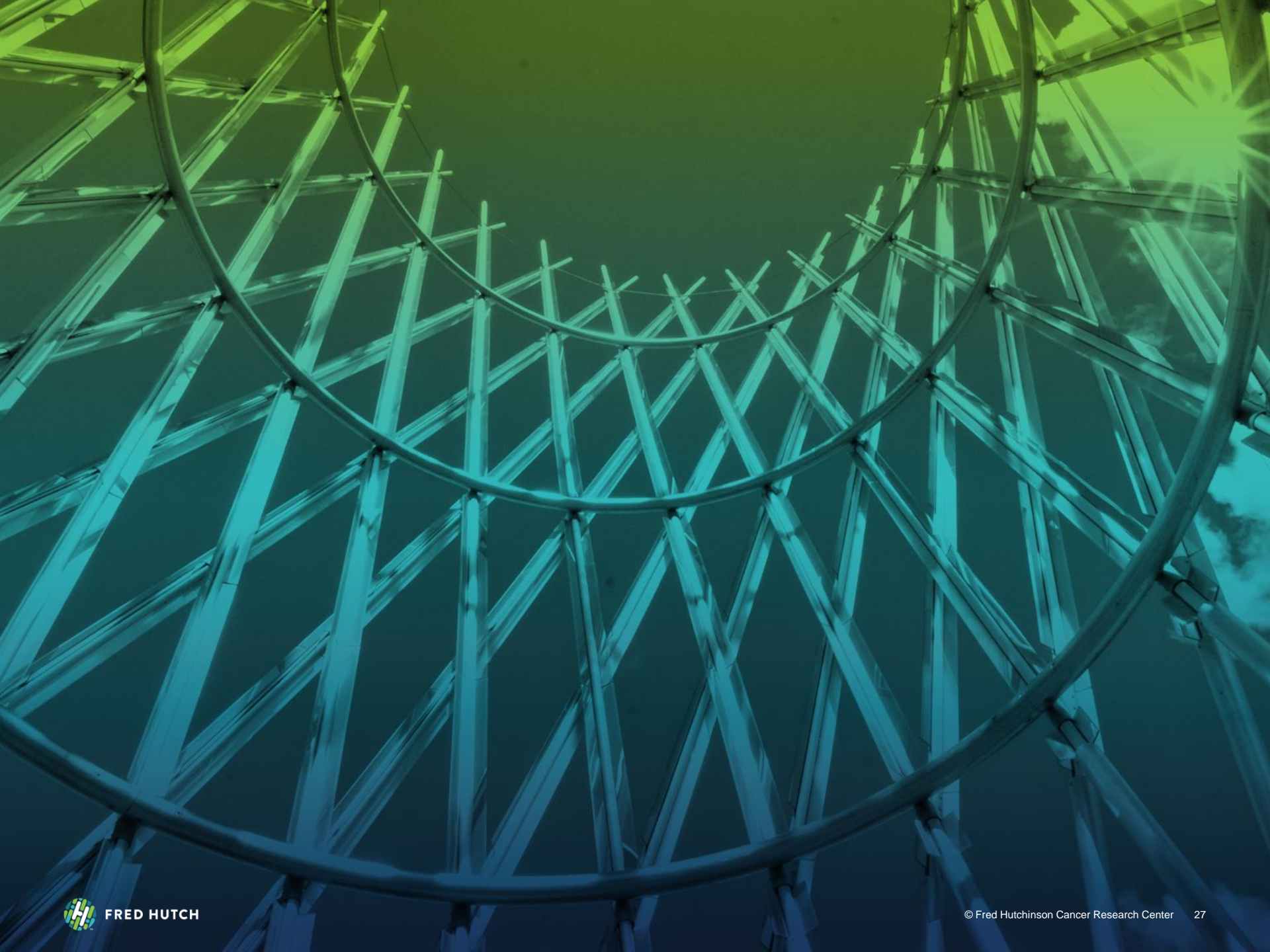
Team

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.