Development and Implementation of Patient-Centered Resources for Cancer Care

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Disclosures

Funding

NIH – NCI (PNW SPORE, CISNET, PROMISS), NIDDK (LURN), AHRQ (EPC)
DOD (GRASP)
Movember Foundation (TrueNTH USA)
American Cancer Society (CLEARPath)
GenomeDX (IMPACT study, SUO CTC)
These results may guide decision making for treatment selection and clinical management of patients with health-related quality-of-life impairments after treatment for localized prostate cancer.
User-Centered Design

Iterative development of new technologies where needs of target users are solicited alongside development
Self-Management and Chronic Disease Care

Wagner E, et al. JAMA 2002
Self-Management and Prostate Cancer Care

Information needs of prostate cancer patients

- Paying for medical care
- Alternative medicine
- Coping with cancer
- Screening and early detection
- Symptoms of cancer
- Treatment of prostate cancer
- General information on prostate cancer
- Causes of cancer
- Long-term side effects
- Effects on partner
- Recurrence of prostate cancer

Pct. of patients

Presentation of Quality of Life Outcomes

Q1: How am I compared with other men?
Q2: What about other parts of my health?
Q3: Do I regret my treatment choice?
Q4: How am I doing compared with before treatment?
Q5: What can I expect in the future?
Q6: How will my treatment affect my partner?

Total N=60

Ranking

Number of men

Presentation of Quality of Life Outcomes


<table>
<thead>
<tr>
<th>Time of survey</th>
<th>John</th>
<th>Men like John</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before treatment</td>
<td>91</td>
<td>91</td>
</tr>
<tr>
<td>Months after treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>65</td>
<td>60</td>
</tr>
<tr>
<td>12</td>
<td>80</td>
<td>75</td>
</tr>
<tr>
<td>18</td>
<td>85</td>
<td>78</td>
</tr>
<tr>
<td>24</td>
<td>85</td>
<td>80</td>
</tr>
<tr>
<td>30</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>48</td>
<td>80</td>
<td></td>
</tr>
</tbody>
</table>

![Image of smiley faces and graphs showing quality of life outcomes over time for John, Men like John, Bill, and Men like Bill.](image)
## Presentation of Quality of Life Outcomes

<table>
<thead>
<tr>
<th></th>
<th>Table</th>
<th>Bar</th>
<th>Line</th>
<th>Pictograph</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helpfulness</td>
<td>2.6 (0.8)</td>
<td>2.9 (0.7)</td>
<td>2.8 (0.8)</td>
<td>2.1 (0.7)</td>
</tr>
<tr>
<td>Confidence in interpretation</td>
<td>2.8 (0.8)</td>
<td>2.8 (0.7)</td>
<td>2.9 (0.8)</td>
<td>2.4 (0.9)</td>
</tr>
<tr>
<td>Preference ranking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>2.7 (0.9)</td>
<td>1.8 (0.9)</td>
<td>2.1 (0.9)</td>
<td>3.4 (1.1)</td>
</tr>
<tr>
<td>Ranked #1</td>
<td>12%</td>
<td>44%</td>
<td>32%</td>
<td>12%</td>
</tr>
</tbody>
</table>

Presentation of Quality of Life Outcomes

How much time do doctors spend per patient?

- 21 minutes or more: 30%
- 17-20 minutes: 21%
- 13-16 minutes: 26%
- 9-12 minutes: 18%
- Less than 9 minutes: 6%

Source: Medscape's Physician Compensation report of 24,216 U.S. physicians

Presentation of Quality of Life Outcomes

Clinician feedback

• Concern about comparison
  • 19/50 (38%)
  • 9/19 Urologists (47%)
• Interruptions to clinic workflow
  • 16/50 (32%)

Presentation of Quality of Life Outcomes

Presentation of Quality of Life Outcomes

## Presentation of Graphical Data

### Correlation coefficients between literacy and dashboard comprehension

<table>
<thead>
<tr>
<th></th>
<th>Overall (n=50)</th>
<th>High GLS</th>
<th>Low GLS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SNS</td>
<td>GLS</td>
<td>SNS</td>
</tr>
<tr>
<td>Overall</td>
<td>0.35</td>
<td>0.59</td>
<td>0.29</td>
</tr>
<tr>
<td>Reading</td>
<td>0.16</td>
<td>0.57</td>
<td>-0.08</td>
</tr>
<tr>
<td>Reading between</td>
<td>0.15</td>
<td>0.35</td>
<td>0.18</td>
</tr>
<tr>
<td>Reading beyond</td>
<td>0.48</td>
<td>0.48</td>
<td>0.34</td>
</tr>
</tbody>
</table>

- **Large**: > 0.50
- **Medium**: 0.30-0.49
- **Low**: (-0.29)-0.29

TrueNTH USA Symptom Tracker

We are interested in some things about you and your health. Please answer all of the questions yourself by selecting the answer that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?</td>
<td>✔️</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have any trouble taking a long walk?</td>
<td></td>
<td>✔️</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have any trouble taking a short walk outside of the house?</td>
<td></td>
<td></td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Do you need to stay in bed or a chair during the day?</td>
<td></td>
<td></td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Do you need help with eating, dressing, washing yourself or using the toilet?</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
</tbody>
</table>

https://us.truenth.org/
TrueNTH USA Symptom Tracker

Biopsy date: 11 Nov 2016
Treatment(s): Start watchful waiting (12 Dec 2016), Radical prostatectomy – nerve sparing (5 Jan 2017)

If your dot is within the blue-grey line, then your symptoms are similar to other men in the United States of all ages, who have had all treatments. If not, your symptoms are better or worse than this.

**Urinary Incontinence**

Your Urinary Incontinence score:
0 on month 3
Overall, you reported that this is big problem for you.

**Sexual**

Your Sexual score:
35 on month 3
Overall, you reported that this is small problem for you.

**Bowel**

Your Bowel score:
0 on month 3
Overall, you reported that this is big problem for you.

**Vitality/Hormonal**

Your Vitality/Hormonal score:
80 on month 3
We do not currently have enough information to show the line for men like you.

https://us.truenth.org/
TrueNTH USA Symptom Tracker

Your Tips & Recommendations

Below are tips specifically personalized for you, based on what you told us about yourself, your treatments, and how you have been doing according to the Symptom Tracker.

Urinary Incontinence

These Urinary incontinence recommendations are tailored for the following:

- More than once per week leakage.
- Using 1 or more pads per day
- Any problems with bloody urine

How can I decrease urine leakage?

Your Response: More than once per week leakage.

Maybe you’ve asked yourself, “What can I do to decrease my urine leakage?” Here are some things you can try to help, especially if you have leakage more than once a week:

1. Empty your bladder every 2-3 hours to keep it from getting too full.
2. When you have a strong urge to urinate, calm the bladder by doing 4-5 gentle tighten-and-release actions using the pelvic floor muscles (sometimes referred to as Kegel exercises).
3. Be prepared when you sneeze or cough by doing a pelvic floor muscle contraction to tell the bladder to hold.
4. Short, one-second pelvic floor contractions (Kegels) can help with leakage episodes.
5. Drink to satisfy thirst, and restrict fluid intake 2-3 hours before going to sleep if nighttime urination is an issue.

Urinary control pads

Your Response: Using 1 or more pads per day

Using 1 or more pads a day can be challenging. The following tips are recommended to help you deal with that:

1. Set up times to do Kegel exercises when you are not doing other things, like driving; do both short (one second) and long (five seconds) pelvic floor contractions.
2. Protect your clothes. Wear bladder control pads during the day; they’re designed to prevent leakage; keep an extra pad, underwear, and pants available in a duffel bag when you’re away from home.
3. Protect your skin. If you need 2 or more pads a day, use products that block moisture from the skin like zinc oxide and A&D ointment.
4. Protect your bed. If you need 3 or more pads a day, keep a urinal next to the bed for nighttime urination; put a waterproof cover on your mattress.

https://us.truenth.org/
http://www.prostatecancerdecision.org/
TrueNTH USA Symptom Tracker

https://us.truenth.org/
TrueNTH USA Symptom Tracker

https://us.truenth.org/
TrueNTH USA Symptom Tracker

*Modules in development*

> Confirmation of graphical concepts among low literacy patients (GRASP)
> Assessment of impact of PRO integration of PRO and clinical outcomes in advanced prostate cancer
> Self-management algorithms for AS maintenance (partnership with PASS)
> Development and implementation of Caregiver Module (CHASM)
> Workflow assessment to construct MOO for other TrueNTH USA sites
TrueNTH USA Symptom Tracker

Patient-Centered Health Information

- Patient knowledge of their PCa diagnosis
  - PSA ~90-100%
  - Gleason score ~50%
  - Biopsy cores ~20%
  - Risk stratification ~20%
Patient-Centered Health Information

Prostate cancer patient understanding of their biopsy report (n=51)
Prostate cancer patient perceptions of the benefits of PC biopsy reports (n=51)
Patient-Centered Health Information

Evidence Review: Who is the audience of pathology reporting?

Four themes identified:

1. Content standardization
2. Variation in pathology report content
3. Communication with clinicians
4. Quality improvement

No literature identified that addressed the patient as a stakeholder

## Patient-Centered Resources for Cancer Care

<table>
<thead>
<tr>
<th>Report</th>
<th>Standard report</th>
<th>Modified report 1</th>
<th>Modified report 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radical nephrectomy</td>
<td>10.8</td>
<td>9.8</td>
<td>9.5</td>
</tr>
<tr>
<td>Partial nephrectomy</td>
<td>10.9</td>
<td>9.9</td>
<td>9.3</td>
</tr>
<tr>
<td>Radical cystectomy</td>
<td>12.0</td>
<td>12.0</td>
<td>12.0</td>
</tr>
<tr>
<td>Radical prostatectomy</td>
<td>10.5</td>
<td>11.5</td>
<td>10.6</td>
</tr>
</tbody>
</table>

Modified report 1: Removed gross and immunohistochemistry content
Modified report 2: Replaced technical cancer terms with lay terms

Patient-Centered Health Information

1. Review existing reports
2. Identify clinically important elements

1. Review existing reports
2. Review clinically important elements
3. Generate candidate reports with patient-centered language

1. Prospective pilot
2. Patients received standard + PC pathology report
3. Outcomes relevant to PC pathology reports
Patient-Centered Health Information

1. Review existing reports
2. Identify clinically important elements

1. Review existing reports
2. Review clinically important elements
3. Generate candidate reports with patient-centered language

1. Prospective pilot
2. Patients received standard + PC pathology report
3. Outcomes relevant to PC pathology reports

Patient-Centered Health Information

Expert panel
1. Review existing reports
2. Identify clinically important elements

Patient Advisory Board
1. Review existing reports
2. Review clinically important elements
3. Generate candidate reports with patient-centered language

Clinic
1. Prospective pilot
2. Patients received standard + PC pathology report
3. Outcomes relevant to PC pathology reports

Patient-Centered Health Information

1. Review existing reports
2. Identify clinically important elements

Patient Advisory Board

1. Review existing reports
2. Review clinically important elements
3. Generate candidate reports with patient-centered language

Clinic

1. Prospective pilot
2. Patients received standard + PC pathology report
3. Outcomes relevant to PC pathology reports

Patient-Centered Health Information

Expert panel

BLADDER CANCER:
  Stage
  Grade

PROSTATE CANCER
  Gleason/ISUP grade
  Number of positive cores

Patient-Centered Health Information

Patient Advisory Board

THEMES
- Narrative format
- Representation of risk
- Figure or table

What are the biopsy results?
Your biopsy shows that you have a diagnosis of bladder cancer. This report provides information about the stage of cancer that you have, describes the grade of the cancer, names the type of cancer, and gives you an idea about the risk of this cancer coming back.

What is the stage of the cancer?
Your tumor stage (T stage) is Ta. Stage means how far the tumor has grown into the layers of the bladder wall. The picture below shows the layers of bladder and yours is growing off the inner urothelium layer.

What is the grade of the cancer?
You have low-grade bladder cancer. Grade tells us how the tumor cells look under the microscope. A low-grade cancer looks and acts more like normal cells, and is less likely to spread. A high-grade cancer means the tumor cells are unorganized and do not look like normal cells. High-grade cancer cells are more likely to multiply and spread.

Do I have a common type of cancer?
This is a common type of bladder cancer found in the majority of patients called: urothelial cell cancer.

What are the chances the tumor will come back?
According to these details, your risk of the tumor coming back is low. Your doctor can tell you a percentage.

What is the bottom line?
This is a Stage Ta, low-grade, urothelial cell bladder cancer.
Patient-Centered Health Information


Correct stage
Correct grade
Correct stage
Correct grade

Pct. Correct

Standard (n=19) Patient-centered (n=20)

* P<0.05

Initial
1 month later
Patent summary of results – Prostate biopsy
Mr. John Doe from August 14, 2015

Why do we do biopsies?
Doctors screen for prostate cancer with a blood test called PSA and a rectal exam. These tests help decide who should have more tests. A biopsy is the main way that we diagnose prostate cancer. These are your results:

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Prostate cancer</th>
<th>Amount: 67% of samples have cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade:</td>
<td>Gleason score 3+4</td>
<td>Risk category: Intermediate risk</td>
</tr>
</tbody>
</table>

What did it show?
Based on looking at your prostate cells under the microscope, there is prostate cancer.

How much cancer is there?
To understand how much of your prostate is involved by cancer, we look at how many biopsy samples had cancer. You had cancer in 8 out of 12 samples (67%).

How bad is it?
Grade tells us how aggressive the tumor cells look under the microscope. Cancers with a higher score are more likely to multiply and spread. In prostate cancer the grade is known as the Gleason Score. This score is made up of two numbers ranging from 3 to 5. The first number shows the most common grade under the microscope and the second number is the next most common grade. The scale starts at Gleason score 3 + 3 = 6 (lowest grade) to Gleason score 5 + 5 = 10 (highest grade). YOUR GLEASON SCORE IS 3 + 4 = 7.

What is the overall risk to my life?
To find your risk, there are many factors to use, such as your PSA, rectal exam (T stage) and your biopsy results. Based on your biopsy results you have intermediate risk disease, but knowing your PSA and rectal exam findings may affect your overall risk. This information should not replace the need to talk to your doctor in more detail.

<table>
<thead>
<tr>
<th>Risk category</th>
<th>Low</th>
<th>Intermediate</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gleason score</td>
<td>3 + 3 = 6</td>
<td>3 + 4 = 7</td>
<td>4 + 4 = 8</td>
</tr>
<tr>
<td>PSA (ng/ml)</td>
<td>&lt;10</td>
<td>10-20</td>
<td>&gt;20</td>
</tr>
<tr>
<td>Clinical T stage (based on rectal exam)</td>
<td>N0/small nodule (T1-2a)</td>
<td>Medium nodule (T2b)</td>
<td>Large nodule (T2c)</td>
</tr>
</tbody>
</table>

Nayak J, et al. GU ASCO 2018
Patient-Centered Health Information

Nayak J, et al. GU ASCO 2018

PROSTATE CANCER

Pct. Correct

Correct Gleason score
Correct positive cores

* P<0.05

Standard (n=40)
Patient-centered (n=39)

Nayak J, et al. GU ASCO 2018
Patient-Centered Health Information

Breast Cancer
- Breast core biopsy
- Breast surgical pathology

Colon Cancer
- Colon polyp
- Colon surgical pathology

Prioritized elements
- Precancerous histology
- Complete resection
- Number

Prioritized elements
- Stage
- Grade
- Nodal status
- Her-2-Neu status
- ER-PR status
- Margin status
- Nodal status
- Complete TME
PCPR Future Directions

Multicenter study
EHR integration
Publicly available website www.pathologytranslator.com
Other cancer sites/specimens
## PCPR Future Directions

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>180,890</td>
<td>Breast</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
<td>117,920</td>
<td>Lung &amp; bronchus</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>70,820</td>
<td>Colon &amp; rectum</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>58,950</td>
<td>Uterine corpus</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>46,870</td>
<td>Thyroid</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>40,170</td>
<td>Non-Hodgkin lymphoma</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>39,650</td>
<td>Melanoma of the skin</td>
</tr>
<tr>
<td>Oral cavity &amp; pharynx</td>
<td>34,780</td>
<td>Leukemia</td>
</tr>
<tr>
<td>Leukemia</td>
<td>34,090</td>
<td>Pancreas</td>
</tr>
<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>28,410</td>
<td>Kidney &amp; renal pelvis</td>
</tr>
<tr>
<td><strong>All Sites</strong></td>
<td>841,390</td>
<td><strong>All Sites</strong></td>
</tr>
</tbody>
</table>
PCPR Backwards Directions

The top 5 most common cancers in male/female (2012)

1. Lung, bronchus, & trachea: 1,241,600
2. Prostate: 1,111,700
3. Colon & rectum: 746,300
4. Stomach: 631,300
5. Liver: 554,400

1. Breast: 1,676,600
2. Colon & rectum: 614,300
3. Lung, bronchus, & trachea: 583,100
4. Cervix uteri: 527,600
5. Stomach: 320,300

http://2016.igem.org/Team:NJU-China/test
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What is the bottom line?

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Patient-Centered Resources for Cancer Care
# Translational PCOR

<table>
<thead>
<tr>
<th>PCOR phases</th>
<th>Bladder cancer</th>
<th>Prostate cancer</th>
<th>Kidney cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>II: Evidence synthesis</td>
<td>NMIBC1</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>III: Comparative effectiveness research</td>
<td>CISTO</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>IV: Patient-centered tools</td>
<td>PCPR</td>
<td>TrueNTH Symptom Tracker PCPR</td>
<td>?</td>
</tr>
</tbody>
</table>
CISTO

Comparison of Intravesical therapy with Surgery as Treatment Options for recurrent bladder cancer

Would you be willing to sign up for a study in which you get one of two treatments:
1) additional treatments delivered into the bladder OR
2) bladder removal

---

Patient Choice

Randomized trial

283 respondents
Patient-Centered Resources for Cancer Care

UW
Andrea Hartzler, PhD
William Lober, PhD
Justin McReynolds
Lawrence True, MD
Danielle Lavallee, PhD
Funda Vakar-Lopez, MD
Sarah Holt, PhD
Bruce Dalkin, MD
Jonathan Wright, MD, MS
Daniel Lin, MD

Residents/fellows
Matt Mossanen, MD
Jason Izard, MD
Jay Nayak, MD
Liam Macleod, MD
Geolani Dy, MD
Daniel Avery, MD
Cheryl Shih, MD
Sean Mikles, MS
Nick Scalzo, BS
Alice Chu, BS

UNC/BCAN
Angie Smith, MD, MS
Diane Quale
Stephanie Chisolm, PhD
Alejandra Spangler
Rick Bangs
Michael Jones, MD