Designing for Dissemination and Implementation: A pragmatic case study for the development and evaluation of a cancer prognostic tool

Insights and Innovation in Improving Health CRISP Seminar Series

Borsika A. Rabin, Ph.D., M.P.H., Pharm.D.

Department of Family Medicine and Adult and Child Center for Health Outcomes Research and Delivery Science, School of Medicine, University of Colorado

www.ucdenver.edu/implementation
Overview

- Defining ‘Designing for Dissemination and Implementation (D&I)’

- The SEER Cancer Survival Calculator – a case study and what we learned

- Resources for Designing for D&I
Designing for D&I defined

#1: Designing for Dissemination and Implementation refers to a set of processes that are considered and activities that are undertaken throughout the planning, development, and evaluation of an intervention to increase its dissemination and implementation potential.¹

#2: Designing for diffusion is the taking of strategic steps early in the process of creating and refining an evidence-based intervention to increase its chances of being noticed, positively perceived, accessed, and tried and then adopted, implemented, and sustained in practice.²

¹http://www.makeresearchmatter.org/glossary.aspx
Designing for D&I

- Plan for D&I from the start
- Engage your target users
- Choosing and integrate a theoretical model/framework
- Use learnings from the DOI literature and social marketing
- Use an iterative approach for the development of your intervention
- Choose measures that matter in the real world
- Choose designs that allow you to generate outcomes that inform real-world performance
- Make it easy on future adopters
Designing for D&I:
The development and evaluation of the SEER Cancer Survival Calculator (SEER CSC)
What is SEER CSC?

- Developed by NCI’s Statistical Research and Applications Branch (led by Rocky Feuer)
- Interactive, web-based system
- Based on SEER and linked Medicare data
- Survival estimates in numerical/graphical format
- Strong emphasis on comorbidities
- Treatment impact is not included
- Currently prostate, colorectal, head and neck cancer
- Finalizing breast cancer
SEER Cancer Survival Calculator (SEER*CSC)
Assesses the impact of cancer and other health conditions on patient survival

What does this site provide?

The SEER Cancer Survival Calculator (SEER*CSC) uses the NCI's Surveillance, Epidemiology and End Results (SEER) data, coupled with Medicare data, to estimate the probabilities of surviving or dying from cancer or from other causes based on a set of patient characteristics. SEER*CSC is designed to estimate the long term prognosis of recently diagnosed patients. 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.

Why Use this Site?

Equal Focus on Cancer and Other Conditions

- As cancers are increasingly diagnosed in early stages, many cancer patients might be surprised to learn that they have a higher chance of dying from conditions other than their cancer.
- Cancer survival statistics often focus only on the cancer. SEER*CSC provides equal focus on the chance of dying of cancer and other causes, and the factors that contribute to each.
- Shows the importance of considering the full spectrum of the patient's health issues, rather than isolating the cancer and its treatment.

Considers the Impact of Coexisting Conditions on Life Expectancy

An unique feature of SEER*CSC is to use a patient's coexisting conditions to compute their "health adjusted age" (a measure of the patients life expectancy independent of their cancer), which is incorporated into the calculations.

Representative of Cancer Patients in the United States

- Estimates are available for groups that are not usually included in trials (e.g., the elderly or those with significant coexisting conditions).
- Because SEER is a large diverse population-based database, the estimates are representative of the United States population.

Steps to use this site

1. Enter patient and disease characteristics.
2. Adjust for health status using coexisting conditions or general health at the time of diagnosis.
3. Generate the results: probabilities of surviving or dying from cancer or other causes from one to ten years.

SEER*CSC provides statistics for the following cancer sites:
- Colorectal Cancer
- Prostate Cancer
- Breast Cancer
- Oral Cancer
Phase II: Clinical Implementation/Health care System Integration

A. Feasibility testing with operational, clinical and IT decision makers (Supplement funded)
   - Study of organizational integration

B1. Small scale implementation (September 2012 Supplement)

B2. Integration into the EMR
   - Call to developers

C. Horizontal scale-up in health care setting
   - Call to health care system providers (Data Palooza 2012)

Health care setting version

Phase III: Web Integration

Concept testing:

What are current physician practices in discussing survival data with patients?

What is the role of co-morbidities in generating prognostic estimates?

What sources are currently being used to provide prognosis to patients?

How should prognosis be presented to patients according to patient advocates?

What are patients needs in terms of prognostic information at the time of diagnosis?

What is the initial reaction of providers, patient advocates and patients to a proof of concept for SEER-CSC?
Phase II: Clinical Implementation/Health care System Integration

Phase 0
Formative Research (NCI testing)

Phase I
Usability/feasibility testing with providers

A. Feasibility testing with operational, clinical and IT decision makers (Supplement funded)
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Phase III: Web Integration

General applicability, content and usability, and implementation potential:

Are there specific usability issues?

Primarily developed for oncologists – can it be relevant to other type of providers and specialties?

Is there a variance in how well it works across different type of settings?

What is the best way to release the tool (stand alone web-based, integrated into health care system)?

Should it be made available to patients and if so how?
Summary of Results

Patient Prognosis

Legend
- number who will likely die from their cancer
- number who will likely die from other health-related causes
- number who will likely survive

1 Year After Diagnosis
- Approximately 3 out of 100 will die from their cancer,
- Approximately 15 out of 100 will die from other causes,
- Approximately 82 out of 100 will survive.

3 Years After Diagnosis
- Approximately 0 out of 100 will die from their cancer,
- Approximately 40 out of 100 will die from other causes,
- Approximately 52 out of 100 will survive.

5 Years After Diagnosis
- Approximately 11 out of 100 will die from their cancer,
- Approximately 88 out of 100 will die from other causes,
- Approximately 31 out of 100 will survive.

Patient Characteristics

Health Status
Adjusted Age: 91

Comorbidities used to calculate health status adjusted age:
- Acute Myocardial Infarction
- Congestive Heart Failure
- Chronic Obstructive Pulmonary Disease
- Rheumatologic Disease
- Diabetes With Sequelae

Modify Health Status

Age at Diagnosis: 71
Race: White
Sex: Female
Marital Status: Married (including common law)

Modify Patient Demographics

Type of Cancer: Colorectal Cancer
Sub Site: Distal (Descending Colon, Sigmoid Colon, Rectosigmoid Junction)
AJCC Stage: Stage IIIA
Grade: High Grade (Poorly Differentiated and Undiff)

Modify Disease Characteristics

Additional Resources

Patient Resources
Physician Resources
Patient Prognosis Estimates

1 Year After Diagnosis
- 7 out of 100 will likely die from cancer
- 10 out of 100 will likely die from other causes
- 83 out of 100 will likely survive

5 Years After Diagnosis
- 27 out of 100 will likely die from cancer
- 37 out of 100 will likely die from other causes
- 36 out of 100 will likely survive

10 Years After Diagnosis
- 31 out of 100 will likely die from cancer
- 56 out of 100 will likely die from other causes
- 13 out of 100 will likely survive

Patient Characteristics

Age at Diagnosis: 55
Health Status Adjusted Age: 83
Life Expectancy Without Cancer: 7 years
Co-morbidities used to calculate health status adjusted age:
- Congestive Heart Failure
- Renal Disease
Race: Black
Sex: Male
Marital Status:
- Not Married (never married, separated, divorced, widowed)
Type of Cancer:
- Colorectal Cancer
Sub Site:
- Proximal (Cecum, Ascending Colon, Hepatic Flexure, Transverse Colon, Splenic Flexure)
AJCC Stage:
- Stage IB (post surgery)
Grade:
- Low Grade (Well or Moderately Differentiated)

Compare Another Patient
Start Over

Visit the Patient Resources and Physician Resources pages for more information.
Implementation potential in the organizational context (operational, clinical, and IT):
What is the decision process used by different healthcare delivery systems to adopt/implement new clinical decision aids?

How long is it expected to take for a clinical decision aid to be implemented in a healthcare delivery system?

What are the organizational and socio-technical facilitators and challenges for the implementation of SEER-CSC in different healthcare delivery systems?

Does likely ease of implementation of the SEER-CSC differ by healthcare delivery system?

What changes to the current SEER-CSC system would increase the likelihood for adoption and implementation by delivery system?

What strategies should be used to introduce SEER-CSC to different stakeholders in different healthcare delivery systems?

Are the included healthcare systems interested in implementing SEER-CSC?
Real world implementation – small scale – how much and why questions:

How **effectively** is SEER-CSC offered to patients as part of standard care at each institution?

**How many providers** learn about SEER-CSC availability, and do differences in either provider or organizational characteristics affect **awareness** of or perceptions of SEER-CSC?

What proportion of providers will make the effort to obtain an access password, use SEER-CSC, and how often?

Are there **certain cancer patient characteristics or timing** that is associated in more use?

What proportion of **different staff groups** (e.g., different specialty and primary care providers, physicians vs. other type of health care providers) use SEER-CSC?

Is SEER-CSC use related to **increased provider efficiency, likelihood, and confidence** in delivering prognostic information?
Small Scale Implementation: Results

Total of 158 providers had login information created in the system

<table>
<thead>
<tr>
<th>Department</th>
<th>Roll-out Meeting</th>
<th>Follow-up email</th>
<th>Other Follow-up Activities</th>
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<tbody>
<tr>
<td>KP Urology</td>
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<tr>
<td>KP Oncology-Physicians</td>
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<tr>
<td>KP Oncology-Nurses</td>
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<td>84</td>
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<tr>
<td>KP Surgery</td>
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<tr>
<td>Penrose Cancer Center-GI</td>
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<tr>
<td>Penrose-Radiation Oncology</td>
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<td>N/A</td>
<td>0</td>
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<tr>
<td>Private Urology Practice 1</td>
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<tr>
<td>Private Urology Practice 2</td>
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<tr>
<td><strong>Total</strong></td>
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<td><strong>110</strong></td>
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# Small Scale Implementation: Results

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<tr>
<th></th>
<th>Data Pull 1</th>
<th>Data Pull 2</th>
<th>Data Pull 3</th>
<th>Data Pull 4</th>
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<td>15</td>
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<td><strong>Type of cancer</strong></td>
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<tr>
<td>Prostate</td>
<td>22</td>
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<td>Colorectal</td>
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<td><strong>Total number of individual providers</strong></td>
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<td><strong>Uses by site:</strong></td>
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<td></td>
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<td>KP Urology</td>
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<td>KP Oncology</td>
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<td>0</td>
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<td>KP Surgery</td>
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<td>0</td>
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<td>Penrose-GI</td>
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<td>0</td>
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<tr>
<td>Penrose-Radiation Oncology</td>
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<td>Private Urology Practice 1</td>
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<td>0</td>
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</tr>
<tr>
<td><strong>Total number of sessions</strong></td>
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<td>8</td>
<td>4</td>
<td>1</td>
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<td><strong>Sessions by site:</strong></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>KP Urology</td>
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<td>5</td>
<td>2</td>
<td>1</td>
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<tr>
<td>KP Oncology</td>
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<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>KP Surgery</td>
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<td>1</td>
<td>0</td>
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<td>Penrose-GI</td>
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<td>3</td>
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<td>Penrose-Radiation Oncology</td>
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</tr>
<tr>
<td>Private Urology Practice 1</td>
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<tr>
<td>Private Urology Practice 2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Small Scale Implementation: Results

- All champions indicated they would recommend SEER-CSC to others
- Moderate number of those who used SEER-CSC during study period
- Discussing cancer prognosis is out of nurses scope of work
- Champions who used SEER-CSC did not use it with a patient in the room
- SEER-CSC needs some redesign to be patient facing
Usability testing with patients:
Would patients use a tool like this?

Would this tool help them discuss their cancer diagnosis with their friends/family/health care team?

What are the health information seeking practices and preferences for patients?

How do patients describe themselves as an advocate?

Would patients be likely to recommend this tool to others?

Phase III: Web Integration

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Phase II: Clinical Implementation/
Health care System Integration

Phase I
Formative Research (NCI testing)

Usability/ feasibility testing with providers

Feasibility/ usability testing with patients and caregivers
- Study of public implementation (KP/CPIC grant application) (KP/ CPIC grant application)

Phase II: Clinical Implementation/
Health care System Integration

Phase I
Formative Research (NCI testing)

Usability/ feasibility testing with providers

Feasibility/ usability testing with patients and caregivers
- Study of public implementation (KP/CPIC grant application) (KP/ CPIC grant application)
Identification of Participants

- Recruitment via champions from two advocacy groups: Prostate Cancer International, Inc. and Fight Colorectal Cancer

- Recruitment process:
  - All participants were active on social media/online forums

<table>
<thead>
<tr>
<th>Process</th>
<th>PCI</th>
<th>FCC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying champions for cancer sites</td>
<td>Contacts made through NCI</td>
<td>Contacts made through NCI</td>
</tr>
<tr>
<td>Champions identified potential participants</td>
<td>Champion individually emailed members of PCI. Potential participants responded to Champion to volunteer.</td>
<td>Usability testing info was advertised on FCC website. Potential participants answered a few questions and Champion sent study staff a spreadsheet of names/email addresses/other info.</td>
</tr>
<tr>
<td>Study staff reached out to potential participants</td>
<td>Champion cc’d study staff on email back to potential participant; staff responded with more info.</td>
<td>Study staff selected a diverse group of potential participants from spreadsheet; reached out to provide more info.</td>
</tr>
<tr>
<td>Usability testing sessions scheduled</td>
<td>Scheduled at convenience of participant</td>
<td>Scheduled at convenience of participant</td>
</tr>
</tbody>
</table>
Usability Testing Process

- Initial email was sent to participant to schedule a time
- Participants met virtually through WebEx to complete usability testing
  - Read the consent and procedures
  - Asked questions about seeking health information
  - Testing of SEER-CSC using case studies; mouse clicks and audio were recorded
- Testing session was 75 minutes

<table>
<thead>
<tr>
<th>Session</th>
<th>Prostate</th>
<th>Colorectal</th>
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</thead>
<tbody>
<tr>
<td>Average session time</td>
<td>74.4 minutes</td>
<td>71.7 minutes</td>
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<tr>
<td>Longest session time</td>
<td>90 minutes</td>
<td>88 minutes</td>
</tr>
<tr>
<td>Shortest session time</td>
<td>57 minutes</td>
<td>59 minutes</td>
</tr>
</tbody>
</table>

- Participants received a $75 gift card to Amazon
Case Study #2

This is a hypothetical case for a colorectal cancer patient. The information below is based on the structure of the Cancer Survival Query System (CSQS). Please enter the information into CSQS as follows:

Demographic characteristics:
Age at diagnosis: **49**
Race: **Caucasian**
Sex: **Male**
Marital Status: **Divorced**

Sub-site:
Rectal

**AJCC stage: Stage 4**

Grade: **Low**

Medical history: (list of comorbidities from Charlson score)
COPD

Discuss with me what the results tell you, what you think about the results, the layout, is it easy to understand, and any other feedback you have.

**Comparison**

For the next task, please compare the prognostic information of this patient, leaving all the demographic information the same, but changing the AJCC stage to **Stage 2**.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Prostate</th>
<th>Colorectal</th>
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<td><strong>Gender</strong></td>
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<td>Male</td>
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<td>3</td>
</tr>
<tr>
<td>Female</td>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
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<tr>
<td>35-44</td>
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<td>1</td>
</tr>
<tr>
<td>45-54</td>
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<td>55-64</td>
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<td>65+</td>
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<tr>
<td><strong>Race/Ethnicity</strong></td>
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<tr>
<td>Non-White</td>
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<tr>
<td>White</td>
<td>7</td>
<td>7*</td>
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<tr>
<td><strong>Stage at Cancer Dx</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>3</td>
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<tr>
<td>Stage II</td>
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<td>Stage III</td>
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<td>Stage IV</td>
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<tr>
<td>Unknown</td>
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<tr>
<td><strong>Time Since Dx</strong></td>
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<tr>
<td>1 year</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
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<td>4 years</td>
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<tr>
<td>5 years</td>
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</table>

*Participant identified with two (White and Non-White)
Patients’ Advocacy and Information Seeking Behavior

• Patients defining themselves as advocates

“I am an advocate because I believe that knowledge not only raises the level of information for me as a patient, but it also helps future patients; so I have been on websites, been on blogs. I was only diagnosed in September, so it has only been in the past 4 or 5 months that I have been aware of this. I intend on participating in the future because I think it benefits all people.”

“Since I’ve had this for 4 years, I have tended to help others out through my journey. I’m involved in a lot of online support groups. Don’t know if you would call that an advocate or not. A lot of people tend to e-mail or call me. We kind of go through the journey together.”

“Everywhere I go, if the person is close to 50, I tell them to have a colonoscopy; and if their friends and people like that I know, I have even offered to drive them. I have offered to sit up with them when they’re going through their preps. Luckily, no one has taken me up on that. Even though I’m just five years out, I feel like I’m still learning things; and as I’m learning things, I am very free with passing out the information to people. But I’m pretty stickler about the colonoscopy.”
Patients’ Advocacy and Information Seeking Behavior

- Patients defining themselves as advocates
- Current sources of information
- Numbers versus Words

“For me because I’m pretty computer literate; and have been for a long time, the first thing I would do before contacting a doctor would be to read everything I could online, both pros and cons.”

“Really, the Internet in general. I know I for my cancer, certainly there is the typical broad medical sites but also there is lots of specific blogs that relate to a variety of disease, of course, yes, Internet searches and the like. I, of course, did speak with doctors quite a bit; but ultimately the data that I got to make a decision came from my research.”

“Initially it comes from the doctor, and then as you start to dive into the Internet and research, you find there are a lot of different opinions out there - you look for the common denominator among multiple sites. You know, to try to determine what the prognosis was for that one particular treatment.”
“It’s actually critical, not so much helpful. If you really want to get ahold of this, unless you want to tell somebody you can do whatever you want to, treat me—it’s critical to have your numbers...It’s essential to have your numbers.”

“ Mostly in numbers-percentages-the number of years that you would anticipate being cancer free.”

“When I was originally presented with the diagnosis, it was presented both in words and numbers. The doctor who was in charge—my urologist at the time—did take me through my biopsy report and gave me the diagnosis.”

“CSQS11: Oh, don’t think there were any numbers used. I think it was mostly words, like, I don’t think I heard 3 out 5 with your diagnosis will survive or anything related to that; but it was a lot of words.

Michelle: O.K. And, was that helpful? Was it helpful to understand or did you prefer numbers?

CSQS11: Oh, no, no, I prefer words.”
SEER*CSC-specific Feedback

• Overall comments on the site were positive; site very easy to use and format/layout was very simple
• Language needs to be simplified; terms/acronyms clearly defined
  • Age limitations for CRC
• Lack of treatment options a barrier to use
• Chart options/years of survival had varying responses
• Comparing another patient also had a mix of responses
• Cancer site buttons need to clearly indicate they link to the calculator

“I would like to make it easier to step through the process. On the first page, it would have said, ‘click here to begin the tool’ or ‘click here to go next.’ Or, ‘click here to continue, start, or step one’ rather than ‘I have colon cancer’ or ‘I have prostate cancer.’”
Implementation-related Findings

- Would you have any concerns about making this tool available to patients on the Internet?
- Do you think this tool would make you better prepared to discuss prognosis and survival with your cancer doctors or family?
- Would access to this tool make you more likely to discuss prognosis and survival with your cancer doctors or family?
- At what stage of the cancer care journey would you consider using this tool? How would you see yourself using this tool?
- Would you recommend this tool to others? Who? Why?

“Would I have an issue with-you’ve gotta be real careful with that-you gotta be real careful with that-I mean, you don’t want to deny this to people if this is something they can use; but I tell you what, I’ve seen people in chat rooms that freak right the hell out; and I was pretty freaked out at one point, okay? But, you get kind of used to dealing with this, walking around with this; and that’s a tough question, but you know if it exists, you should probably put it out there.”

“No, I wouldn’t. I wouldn’t have any concerns about it. What concerns me-why I tell people to stay away from the Internet for the first little while is because sometimes you get into some pretty depressing chat rooms and groups—that you really need to just stick with basic information for a little while until you can process a little bit more. But this is basic information; and so, I think it would be quite appropriate to start here if you didn’t have a plan.”

“If my doctor had said: You know, there’s a lot of stuff out there on the Internet, which we all know; and a lot of it is written in very scary language. Go to this website, I endorse this highly—and I don’t even know they can do that—but this one will help you from the very beginning.”
Implementation-related Findings

• Would you have any concerns about making this tool available to patients on the Internet?
• Do you think this tool would make you better prepared to discuss prognosis and survival with your cancer doctors or family?
• Would access to this tool make you more likely to discuss prognosis and survival with your cancer doctors or family?

• “If you have more information, you are more able to talk about things with people, basically. And, again, you have knowledge to talk with your doctor. So, you feel confident in a question and answer thing. Your family is a little different. They may have questions, too, but more likely they are going to be more worried and more emotion involved. You need some facts…if you are calm and collected person, the facts are going to calm them down. If everybody is emotional, everyone is going to be a mess regardless. Information is power, that’s for sure.”

“Or, this is something that could be share with the family, and based on this, it could bring up a discussion. I can see myself sitting down with my family and saying, this is kind of a scenario of ways it can go, and getting support and feedback from my family, too.”
Implementation-related Findings

“I would use it right off the bat. As soon as you’re diagnosed, and you’ve got that information.”

“As soon as I’m diagnosed, I’d like to know.”

“All stages. For instance, this is very helpful to me but 5 years out, it would be interesting to see if those prognoses still hold or if they changed because of better outcomes or treatment options. I think it’s all stages. I think it’s really critical for the person who has just been diagnosed. It becomes interesting to people after that. In terms of just being diagnosed, you really want to have an effective tool. That’s when you want to reach people.”

“I would think that this would be really good not right after diagnosis; because right after diagnosis, you’re not quite ready for this kind of information, maybe; I would say maybe once you start treatment and are actually established with a doctor. I think this would be a good thing for doctors to say, hey, if you want more information, this is a good website.”

• At what stage of the cancer care journey would you consider using this tool? How would you see yourself using this tool?
  • Would you recommend this tool to others? Who? Why?
Implementation-related Findings

“I would share it with those who were **newly diagnosed**. Because it seems that what it is geared for. **It doesn’t seem like it’s geared for people who have been dealing with this for 4, 5, 8 years.**”

“I probably would **post it on my Facebook**. I have a prostate cancer Facebook page. Men who contact me-we have a discussion about it. **I probably would share that with them-share it among other resources.**”

“**Anybody who just got diagnosed** with cancer like I did-with almost no understanding of what that meant.”

“And, I think it’s easy enough because they’re at the same stage that you are at-disbelief, confusion, and mad; and they’re going through the same thing and but they don’t know why, because they don’t have it. **But everything is on here, and it’s explaining it.** Yea, I think the caregivers-I think it would be a good site for them to go to also.”

- Would you recommend this tool to others? Who? Why?
Phase II: Clinical Implementation/Health care System Integration

Phase I
Usability/feasibility testing with providers

A. Feasibility testing with operational, clinical and IT decision makers (Supplement funded)
   - Study of organizational integration

B. Release on the web
   - World Wide Web version

C. Horizontal scale-up in health care setting
   - Call to health care system providers (Data Palooza 2012)

Phase III: Web Integration

Feasibility/usability testing with patients and caregivers
   - Study of public implementation (KP/CPIC grant application) (KP/CPIC grant application)

B. Release on the web
   - World Wide Web version
What can we learn from the SEER-CSC experience?

• Early and ongoing engagement of various stakeholders
• Iterative process in the development of the end product
• Measurement and documentation of D&I and stakeholder relevant outcomes
• Guidance to future adopters on implementation
• Interdisciplinary collaboration and study team
• PLUS: some extra activities were added
Predicting Cancer Prognosis Using Interactive Online Tools: A Systematic Review and Implications for Cancer Care Providers

Borsika A. Rabin¹, Bridget Gaglio², Tristan Sanders², Larissa Nekhlyudov³, James W. Dearing¹, Sheana Bull³, Russell E. Glasgow³, and Alfred Marcus³

Abstract

Cancer prognosis is of keen interest for patients with cancer, their caregivers, and providers. Prognostic tools have been developed to guide patient-physician communication and decision-making. Given the proliferation of prognostic tools, it is timely to review existing online cancer prognostic tools and discuss implications for their use in clinical settings. Using a systematic approach, we searched the Internet, Medline, and consulted with experts to identify existing online prognostic tools. Each was reviewed for content and format. Twenty-two prognostic tools addressing 89 different cancers were identified. Tools primarily focused on prostate (n = 11), colorectal (n = 10), breast (n = 8), and melanoma (n = 6), although at least one tool was identified for most malignancies. The input variables for the tools included cancer characteristics (n = 22), patient characteristics (n = 18), and comorbidities (n = 9). Effect of therapy on prognosis was included in 15 tools. The most common predicted outcome was cancer-specific survival/mortality (n = 17). Only a few tools (n = 4) suggested patients as potential target users. A comprehensive repository of online prognostic tools was created to understand the state-of-the-art in prognostic tool availability and characteristics. Use of these tools may support communication and understanding about cancer prognosis. Dissemination, testing, refinement of existing, and development of new tools under different conditions are needed. Cancer Epidemiol Biomarkers Prev;
This website was designed to help healthcare professionals choose among available interactive cancer prognostic tools. Interactive cancer prognostic tools use an algorithm to calculate likely cancer-related outcomes based on a patient’s characteristics.

Use of these tools may support communication and understanding about cancer prognosis. Some of the tools can be used to support shared decision making with cancer patients. The website allows for the comparison of cancer site specific tools or search of tools using your own criteria.

To learn more: www.cancercalculators.org
The Surveillance, Epidemiology, and End Results Cancer Survival Calculator SEER*CSC: Validation in a Managed Care Setting

Eric J. Feuer, Borsika A. Rabin, Zhaohui Zou, Zhuoqiao Wang, Xiaqin Xiong, Jennifer L. Ellis, John F. Steiner, Laurie Cynkin, Larissa Neklyudov, Elizabeth Bayliss, Benjamin F. Hankey

Correspondence to: Benjamin F. Hankey, ScD, CANSTAT, 6805 Colonnade Drive, Plano, TX 75024 (e-mail: bhankey0411@aol.com).

Background

Nomograms for prostate and colorectal cancer are included in the Surveillance, Epidemiology, and End Results (SEER) Cancer Survival Calculator, under development by the National Cancer Institute. They are based on the National Cancer Institute’s SEER data, coupled with Medicare data, to estimate the probabilities of surviving or dying from cancer or from other causes based on a set of patient and tumor characteristics. The nomograms provide estimates of survival that are specific to the characteristics of the tumor, age, race, gender, and the overall health of a patient. These nomograms have been internally validated using the SEER data. In this paper, we externally validate the nomograms using data from Kaiser Permanente Colorado.

Methods

The SEER Cancer Survival Calculator was externally validated using time-dependent area under the Receiver Operating Characteristic curve statistics and calibration plots for retrospective cohorts of 1102 prostate cancer and 990 colorectal cancer patients from Kaiser Permanente Colorado.

Results

The time-dependent area under the Receiver Operating Characteristic curve statistics were computed for one, three, five, seven, and 10 year(s) postdiagnosis for prostate and colorectal cancer and ranged from 0.77 to 0.89 for death from cancer and from 0.72 to 0.81 for death from other causes. The calibration plots indicated a very good fit of the model for death from cancer for colorectal cancer and for the higher risk group for prostate cancer. For the lower risk groups for prostate cancer (<10% chance of dying of prostate cancer in 10 years), the model predicted slightly worse prognosis than observed. Except for the lowest risk group for colorectal cancer, the models for death from other causes for both prostate and colorectal cancer predicted slightly worse prognosis than observed.

Conclusions

The results of the external validation indicated that the colorectal and prostate cancer nomograms are reliable tools for physicians and patients to use to obtain information on prognosis and assist in establishing priorities for both treatment of the cancer and other conditions, particularly when a patient is elderly and/or has significant comorbidities. The slightly better than predicted risk of death from other causes in a health maintenance organization (HMO) setting may be due to an overall healthier population and the integrated management of disease relative to the overall population (as represented by SEER).

Health-Care Utilization by Prognosis Profile in a Managed Care Setting: Using the Surveillance, Epidemiology and End Results Cancer Survival Calculator SEER*CSC

Borsika A. Rabin, Jennifer L. Ellis, John F. Steiner, Larissa Nekhlyudov, Eric J. Feuer, Benjamin F. Hankey, Laurie Cynkin, Elizabeth Bayliss

Correspondence to: Borsika A. Rabin, PhD, MPH, University of Colorado, Anschutz Medical Campus, UPI Building, Mailstop F-443, 13199 E Montview Blvd, Suite 300, Aurora, CO 80045 (e-mail: borsika.rabin@ucdenver.edu).

Background
Accurate estimation of the probability of dying of cancer versus other causes is needed to inform goals of care for cancer patients. Further, prognosis may also influence health-care utilization. This paper describes health service utilization patterns of subgroups of prostate cancer and colorectal cancer (CRC) patients with different relative probabilities of dying of their cancer or other conditions.

Methods
A retrospective cohort of cancer patients from Kaiser Permanente Colorado were divided into three groups using the predicted probabilities of dying of cancer and other causes calculated by the nomograms in the National Cancer Institute Surveillance, Epidemiology and End Results Cancer Survival Calculator. Demographic, disease-related characteristics, and health service utilization patterns were described across subgroups.

Results
The cohort consisted of 2092 patients (1102 prostate cancer and 990 CRC). A new diagnosis of cancer increased utilization of cancer-related services with rates as high as 9.1/1000 person-days for prostate cancer and 36.2/1000 person-days for CRC. Little change was observed in the number of primary and other specialty care visits from prediagnosis to 1 and 2 years postdiagnosis.

Conclusions
We found that although a new diagnosis of cancer increased utilization of cancer-related services for an extended time period, the timing of cancer diagnosis did not appear to affect other types of utilization. Future research should assess the reason for the lack of impact of cancer and unrelated comorbid conditions on utilization and whether desired outcomes of care were achieved.

Resources for Designing for D&I
Designing for Diffusion of a Biomedical Intervention

James W. Dearing, PhD, Dawn K. Smith, MD, MS, MPH, R. Sam Larson, PhD, Carole A. Estabrooks, RN, PhD

Dissemination must be planned and intentional or it will not occur in a systematic manner. And upfront planning makes all the difference.1

Diffusion is a social process that occurs among people in response to learning about an innovation such as a new evidence-based intervention.2 Researchers have conceptualized diffusion either at the macro-sociologic level of societal sector or system and the importance of norms and associations,2 the communicative level of relationships and how those patterned link-}

Designing for Dissemination Among Public Health Researchers: Findings From a National Survey in the United States

The effective dissemination of information on priorities, health risks, and evidence-based interventions in public health is a formidable challenge. Dissemination is an active approach of spreading evidence-based information to the target audience via determined channels using planned strategies. Studies from both clinical and public health settings suggest that evidence-based practices are not being disseminated effectively. For example, in a study of US adults, only 55% of overall care received was based on what is recommended in the scientific literature. In a study of US public health departments, an estimated 58% of programs and policies were reported as “evidence-based.”

To illustrate the dissemination challenges

Objectives. We have described the practice of designing for dissemination among researchers in the United States with the intent of identifying gaps and areas for improvement.

Methods. In 2012, we conducted a cross-sectional study of 266 researchers using a search of the top 12 public health journals in PubMed and lists available from government-sponsored research. The sample involved scientists at universities, the National Institutes of Health, and the Centers for Disease Control and Prevention in the United States.

Results. In the pooled sample, 73% of respondents estimated they spent less than 10% of their time on dissemination. About half of respondents (53%) had a person or team in their unit dedicated to dissemination. Seventeen percent of all respondents used a framework or theory to plan their dissemination activities. One third of respondents (34%) always or usually involved stakeholders in the research process.

Published in final edited form as:


**Designing for Diffusion: How Can We Increase Uptake of Cancer Communication Innovations?**

James W. Dearing and
Kaiser Permanente Colorado, Denver Colorado USA

Matthew W. Kreuter
Washington University, St. Louis, Missouri, USA

**Abstract**

**Objective**—The best innovations in cancer communication do not necessarily achieve uptake by researchers, public health and clinical practitioners, and policy makers. This paper describes design activities that can be applied and combined for the purpose of spreading effective cancer communication innovations.
Development of a Planning Tool to Guide Research Dissemination

Deborah Carpenter, Veronica Nieva, Tarek Albaghal, Joann Sorra

Abstract

Investigation in patient safety improvement is constantly yielding new research results, yet efforts to put the results into practice are inconsistent. Therefore, a pragmatic tool is needed. The Dissemination Planning Tool was developed to assist the Agency for Healthcare Research and Quality (AHRQ) Patient Safety grantees with disseminating their research results. It was designed to help researchers consider major areas in dissemination: packaging research results, identifying target users, engaging connector organizations, identifying barriers, developing success measures, and allocating resources to implement the plan. Developing the tool included several stages, beginning with adapting Rogers’ seminal diffusion theory. Literature was reviewed from health care, sociology, organizational development, psychology, and social sciences, thus providing a breath of dissemination theory and practices. Tools currently used in field-specific instances were reviewed. All of these sources were synthesized through a process of refinement, expert review, and testing.

Advances in Patient Safety: Vol. 4
"Despite the nostalgic myth of the lone genius, successful projects are done in groups. If you can foster hot groups in your organization, you can build your own innovation factory." - Tom Kelley and Jonathan Littman
Knowledge Translation Planning Template©

INSTRUCTIONS: This template was designed to assist with the development of Knowledge Translation (KT) plans for research but can be used to plan for non-research projects. The Knowledge Translation Planning Template is universally applicable to areas beyond health. Begin with box #1 and work through to box #13 to address the essential components of the KT planning process.

<table>
<thead>
<tr>
<th>(1) Project Partners</th>
<th>(2) Degree of Partner Engagement</th>
<th>(3) Partner(s) Roles</th>
<th>(4) KT Expertise on Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ researchers</td>
<td>□ from idea formulation straight through</td>
<td>□ What do the partner(s) bring to the project?</td>
<td>□ scientist(s) with KT expertise</td>
</tr>
<tr>
<td>□ consumers - patients/families</td>
<td>□ after idea formulation &amp; straight through</td>
<td>□ How will partner(s) assist with developing, implementing or evaluating the KT plan?</td>
<td>□ consultant with KT expertise</td>
</tr>
<tr>
<td>□ the public</td>
<td>□ at point of dissemination &amp; project end</td>
<td>Consider: Not all partners will be engaged at the same point in time. Some will be collaborators, end users or audiences, or people hired to do specific activities.</td>
<td>□ knowledge broker/specialist</td>
</tr>
<tr>
<td>□ decision makers</td>
<td>□ beyond the project</td>
<td>□ Action: Capture their specific roles in letters of support to funders, if requested.</td>
<td>□ KT supports within the organization(s)</td>
</tr>
<tr>
<td>□ private sector/industry</td>
<td></td>
<td></td>
<td>□ KT supports within partner organization(s)</td>
</tr>
<tr>
<td>□ research funding body</td>
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<td></td>
<td>□ KT supports hired for specific task(s)</td>
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<td>□ volunteer health sector/NGO</td>
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<td>□ practitioners</td>
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<tr>
<td>□ other</td>
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</table>

Notes: To download the form and learn more: http://www.melaniebarwick.com/training.php
This interactive website was designed to help researchers and practitioners to select the D&I Model that best fits their research question or practice problem, adapt the model to the study or practice context, fully integrate the model into the research or practice process, and find existing measurement instruments for the model constructs. The term 'Models' is used to refer to both theories and frameworks that enhance dissemination and implementation of evidence-based interventions more likely.

To learn more: www.dissemination-implementation.org
Call for Resources

Participants at the recent NIH/VA measures and reporting standards working meeting identified a need for resources that synthesize evaluation tools as a priority area for the field of Dissemination and Implementation Science. A subgroup of participants, led by Drs. Borsika Rabin and Cara Lewis, are working to identify and summarize existing quantitative, qualitative, and mixed methods resources for broad dissemination.

To ensure that no existing resources are overlooked, we ask that you email us with any resources (completed or in progress) you know about or have created for inclusion in this summary article.

We are interested in resources, not individual instruments or measures. Examples of the kind of resources we are looking for include:

- Online repositories of quantitative instruments
  - NCI Grid-Enabled Measures Project
  - Seattle Implementation Research Collaborative Instrument Review Project
- Qualitative coding systems
  - Consolidated Framework for Implementation Research Qualitative Coding Guide

Please forward this Call for Resources to your D&I networks.

Send resources or questions to: borsika.a.rabin@gmail.com or lewiscc@indiana.edu

BY MARCH 16TH
Welcome to GEM, a web-based collaborative tool containing behavioral, social science, and other relevant scientific measures.

The goal of GEM is to support and encourage a community of users to drive consensus on best measures and share the resulting data from use of those measures.

GEM enables users to:

- Add constructs or measures to the database
- Contribute to and update existing information (metadata) about constructs and measures
- Rate and comment on measures to drive consensus on best measures
- Access and share harmonized data
- Search for and download measures

Learn more about GEM

Measures at a Glance

http://www.gem-beta.org/GEM-DI
Instrument Review Project

The SIRC Instrument Review Project: A Systematic Review of Dissemination and Implementation Science Instruments

Video of Instrument Review Taskforce at SIRC 2011
Power Point Presentation from ABCT
SIRC IRP Update 2013 (video of full presentation coming soon).

Exciting advances have been made in the field of dissemination and implementation (D&I). However, much like the science-practice gap that motivates our field, a communication gap exists among stakeholders at the forefront of this work. Measurement issues have slowed the progression of the field of D&I given the laborious process of systematically developing psychometrically sound yet feasible and cost-effective ways to assess our efforts. The lag that occurs between initial development, implementation, and then publication delays the process further, resulting in instances in which independent research teams are devoting considerable resources to unnecessarily redundant work. As a consequence, progress toward the development of commonly used instruments has been very slow, limiting the extent to which researchers have access to and are able to

http://www.seattleimplementation.org/sirc-projects/sirc-instrument-project/
Acknowledgement

Most of the work presented here was funded through the National Cancer Institute (project number 1P20 CA137219) and was inspired and supported by many colleagues from around the country.

Michelle Henton

Bridget Gaglio

Russ Glasgow

Jim Dearing

Tristan Sanders

Sara Hoerner

Al Marcus

Sheana Bull

Larissa Nekhlyudov

Rocky Feuer

Laurie Cynkin

Ben Hankey

Ginger Carter

Brad Hesse

Prostate Cancer International, Inc

Fight Colorectal Cancer
WHAT DO YOU THINK?

GET IN TOUCH:
borsika.rabin@ucdenver.edu
Designing for D&I

(1) an active, systematic, planned and controlled approach
(2) planning for D&I in the early stage of conceptualization and development of the intervention
(3) early involvement of and partnership with target users in the conceptualization and development
(4) close understanding of and building on the characteristics, beliefs, norms, and wants of target adopters
(5) study designs and measures that generate practice-relevant evidence facilitate and inform later-stage D&I efforts

http://www.makeresearchmatter.org/glossary.aspx