



Patient-centered Decision Support Systems

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SINI2014:

Informatics Enabling Patient-Centered Care
Across the Continuum

Topics for today

- Introduction to decision support
 - Review of decision aids available for a variety of health decisions
 - An in-depth look at the development and testing of a specific decision support system for the most common invasive cancer diagnosed in the United States
-

Adapted Ottawa Decision Support Framework

Decisional Needs

Uncertainty related to outcome
Uncertainty related to potential adverse outcomes
Lack of knowledge
Expectations
Personal preferences and factors
Physician factors
Setting and Clinician Resources

High Quality

Informed
Consistent with patient personal preferences & values
Timely
Patient satisfaction with process
Guideline-consistent
Appropriate use of resources

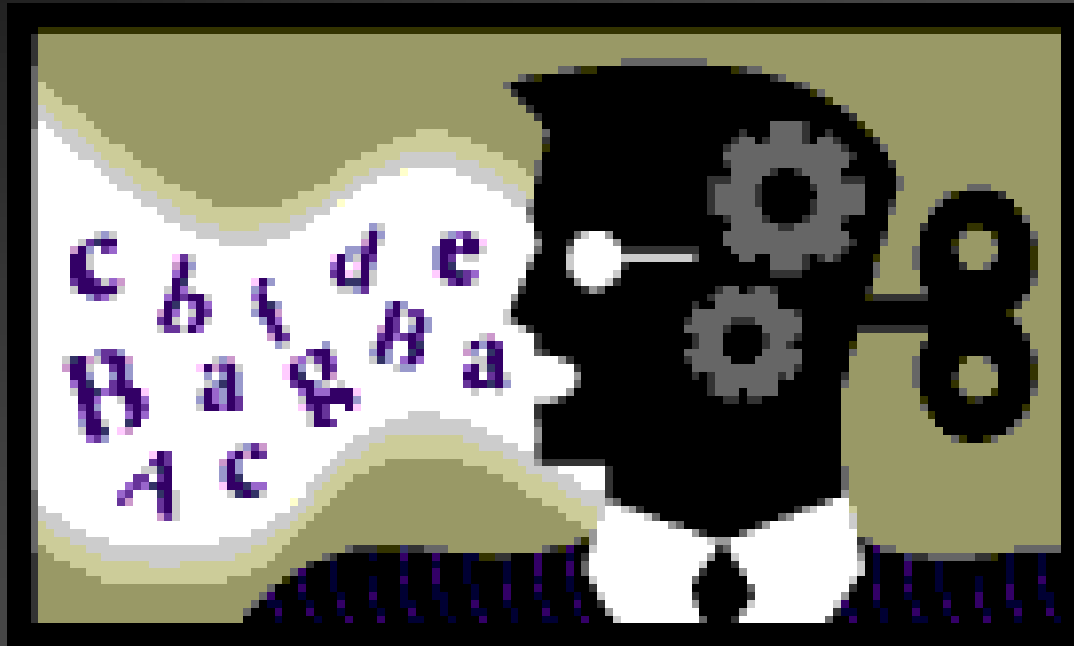
Provide & explain medical facts
Customized coaching for communication
Clarify & communicate personal preferences & factors

Intervention

The best way to....

- Inform; educate?
 - Coach?
 - Clarify personal values?
-

“Let me tell you what you need to know”



“Let me set you up with some information”

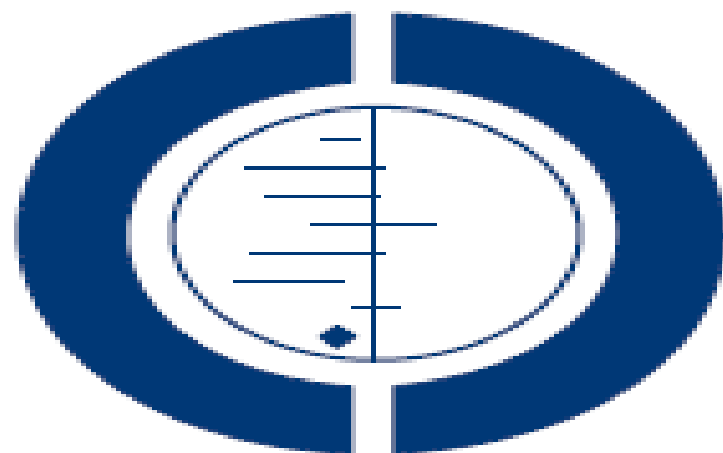


Decisions, decisions....

- Teaching patients about the medical aspects (factors) of their condition is not enough.
 - Synthesis of all sets of factors is required: placing the condition in one's own life context
 - Can individuals do it alone?
 - Do we have enough physicians and nurses who can give customized counseling to each individual?
 - Can informatics help us?
-

Decision aids for people facing health treatment or screening decisions (Review)

Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JHC



**THE COCHRANE
COLLABORATION®**

This is a reprint of a Cochrane review, prepared and maintained by The Cochrane Collaboration and published in *The Cochrane Library* 2014, Issue 1

<http://www.thecochranelibrary.com>

WILEY

Bottom line - Cochrane Review

When using decision aids, compared to usual care there is

High quality evidence for:



Knowledge of options



Decisional conflict

Bottom line - Cochrane Review

When using decision aids, compared to usual care there is

Moderate quality evidence for:



Active engagement in the decision



Accuracy of risk perceptions with probabilities

Bottom line - Cochrane Review

When using decision aids, compared to usual care there is

Low quality evidence for:



Congruence between values and choice

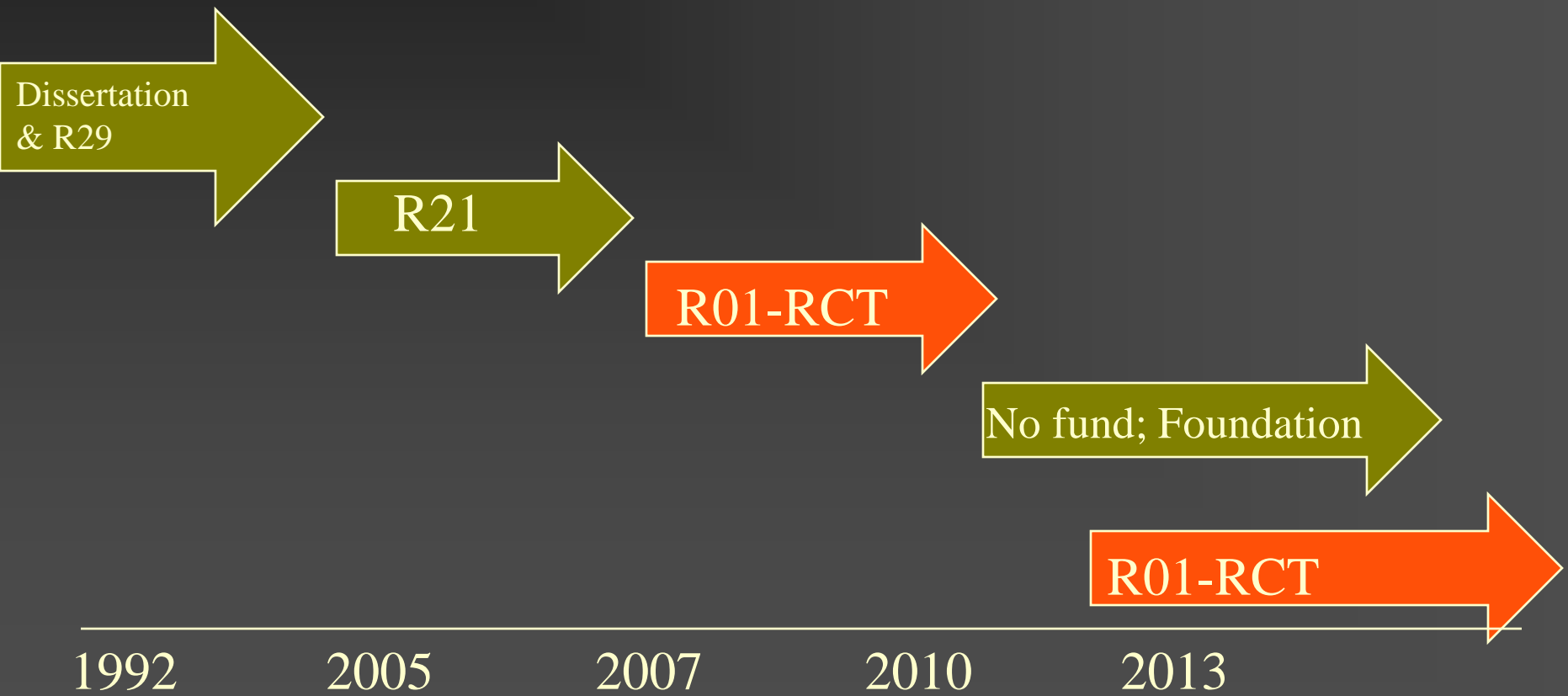
Cochrane Review

- 115 randomized controlled trials
 - 34,444 participants
 - Majority conducted in English-speaking countries
- All studies evaluated patient decision aids that included option information, outcomes and at least implicit values clarification
- Most all included information on the clinical problem as well as outcome probabilities

Localized Prostate Cancer: The Ultimate Treatment Decision



A 22 year journey in decision support



How Do Clinicians and Men With Prostate Cancer Decide About Treatment?

- Age, pathology and co-morbidity are priority considerations for clinicians. Anecdotal stories about personal characteristics (e.g. marathon runner)
- In 1992 (dissertation), I heard from men with prostate cancer that they discussed their detection, diagnosis and decision experiences with other men at work in order to hear about peer experiences.
- We didn't know whether these peer experiences or any other personal factors were key to the decision: we didn't what we didn't know.....





*Nursing Support of Treatment
Decision Making in
Men with Prostate Cancer*

R29 CA 77372

1998-2003



Qualitative:
Patients



Qualitative:
MD's



Quantitative



Pilot
Intervention

Aim 1: Inductive, hypothesis generating phase

- 5 Focus groups and 31 individual interviews
 - Content analysis & grounded theory methods;
 - Unstructured groups and interviews
 - Nud*ist 4 software
 - Audit trail, inter-rater reliability in coding, member checks
 - Purposive and theoretical sampling

The Influential Other (IO)

As early as the 1st focus group, men were talking about hearing stories from other people with cancer. The *Influential other's* experience or advice was **strongly considered by majority**; 20 of the 44 participants used the stories from *influential others* to either *widen their horizons, move toward or away from a specific treatment modality*. The *IO* was typically not the MD.

- When reporting the IO's story the participants stated similar experiences and/or personal relatedness for their lives contexts
 - "...my mom came down with breast cancer at 55. The treatment killed her, radiation, a bad machine at the hospital. But, so, gee, here I am and I'm genetically very much like my mom."
 - "....he's the type like me, he sees the sex thing as the least of his worries."

The Decision Process – Individual Interviews

13

Talk

With one or more MD specialist

25
25

Read-

Books, Internet, magazines

26

Talk

With friends &/or family &/or other men with prostate cancer

31
31

Talk with Urologist

D
E
C
I
D
E

Men who did not read anything

- 6 participants stated that they did not read any written material. All 6 were men of color. 1 first generation Asian-American and 5 African-American men
 - **62 yo:** I feel_ I felt like I was rushed into an operation. I don't blame the doctors, I blame myself. Because, instead of me saying, well I would look into this, I just accepted the doctor's word.
 - **75 yo:** I felt that I had enough information from the doctor that I didn't need to do a lot of additional research of my own to make a decision.
 - **64 yo:** (Responding to query about reading or gathering other information) No I haven't... I was going to tell that doctor I want to go with the best that they had...would be the best for me. That's what I was going to tell them.

Men who were concerned about spread of tumor

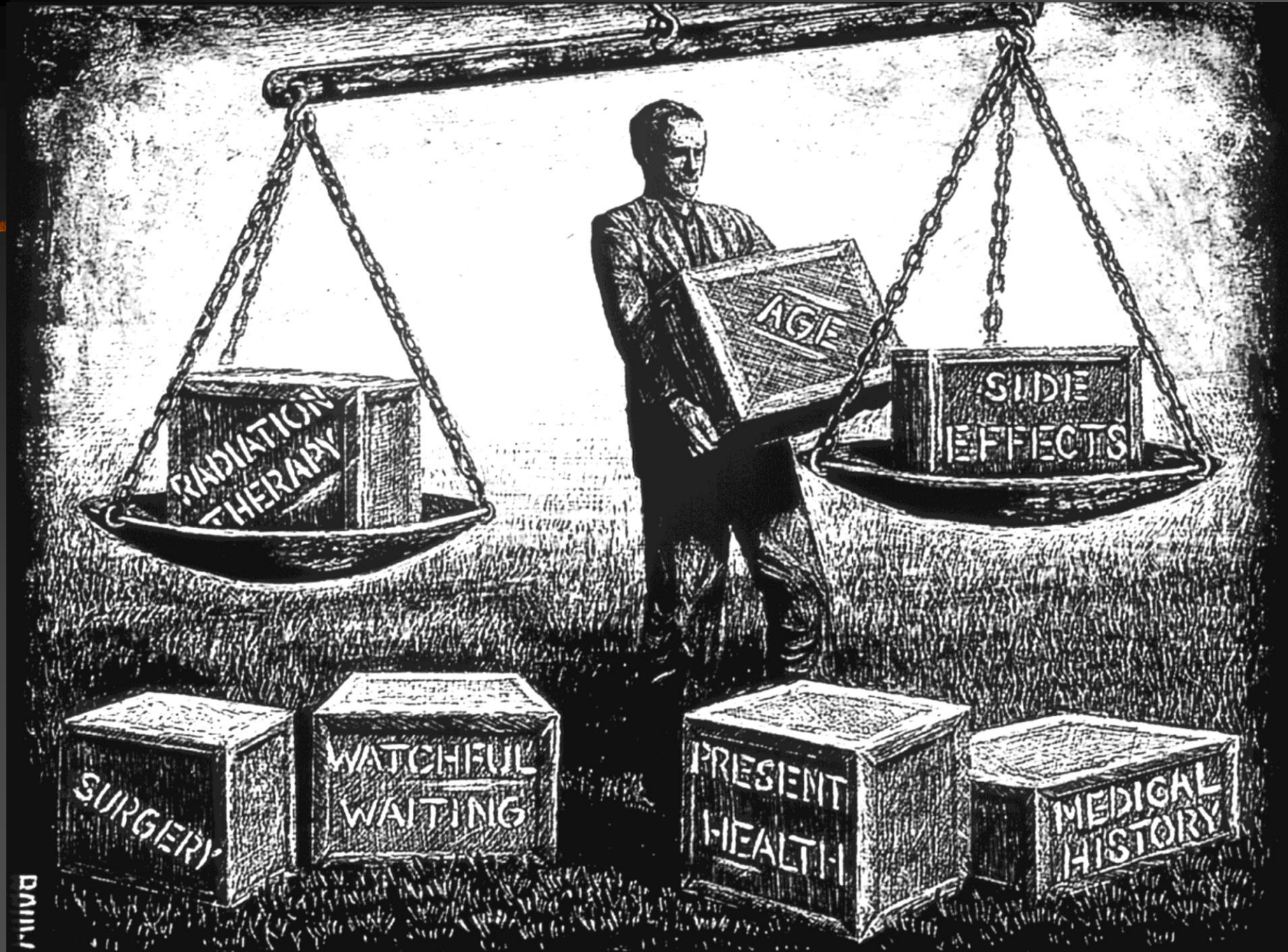
- The 2nd most common outcome concern was “spread”
 - 6 of 7 men of color and 5 of 24 Caucasian men
 - These 6 men of color were the same participants who did not read any written or electronic material as part of information gathering. One African-American participant stated:
 - *“I felt that I had enough information from the doctor that I didn't need to do a lot of additional research of my own to, you know, to make a decision. I've had a couple of friends that have died of prostate cancer, and I didn't know a lot about it. What I did know is that if you neglect it and let it go you're pretty much signing your own death warrant because once it starts to spread it's like any other cancer, once it starts spreading you have a more difficult time trying to get rid of it.”*

Findings from qualitative analysis

Process and Personal Factors

Core decision-making process: “Making the best choice for someone like me”

- Utilization of a wide variety of information sources
- Influence of *who I am* and *what I do*
- Influence of potential treatment complications
- Influence of another’s story or recommendation



Core decision-making process: “Making the best choice for someone like me”

- Men are compelled to place the diagnosis and all the potential outcomes in the context of their own lives (their personal environment), socially and culturally bound...
 - What prostate cancer or other cancer has meant to them in the past
 - ‘Who I am’ and ‘what I do’ determines perspective
 - Guidance sought from others who have some similar contexts
 - Force MD to step into their contexts with the question, ‘what would you do if you were me?’

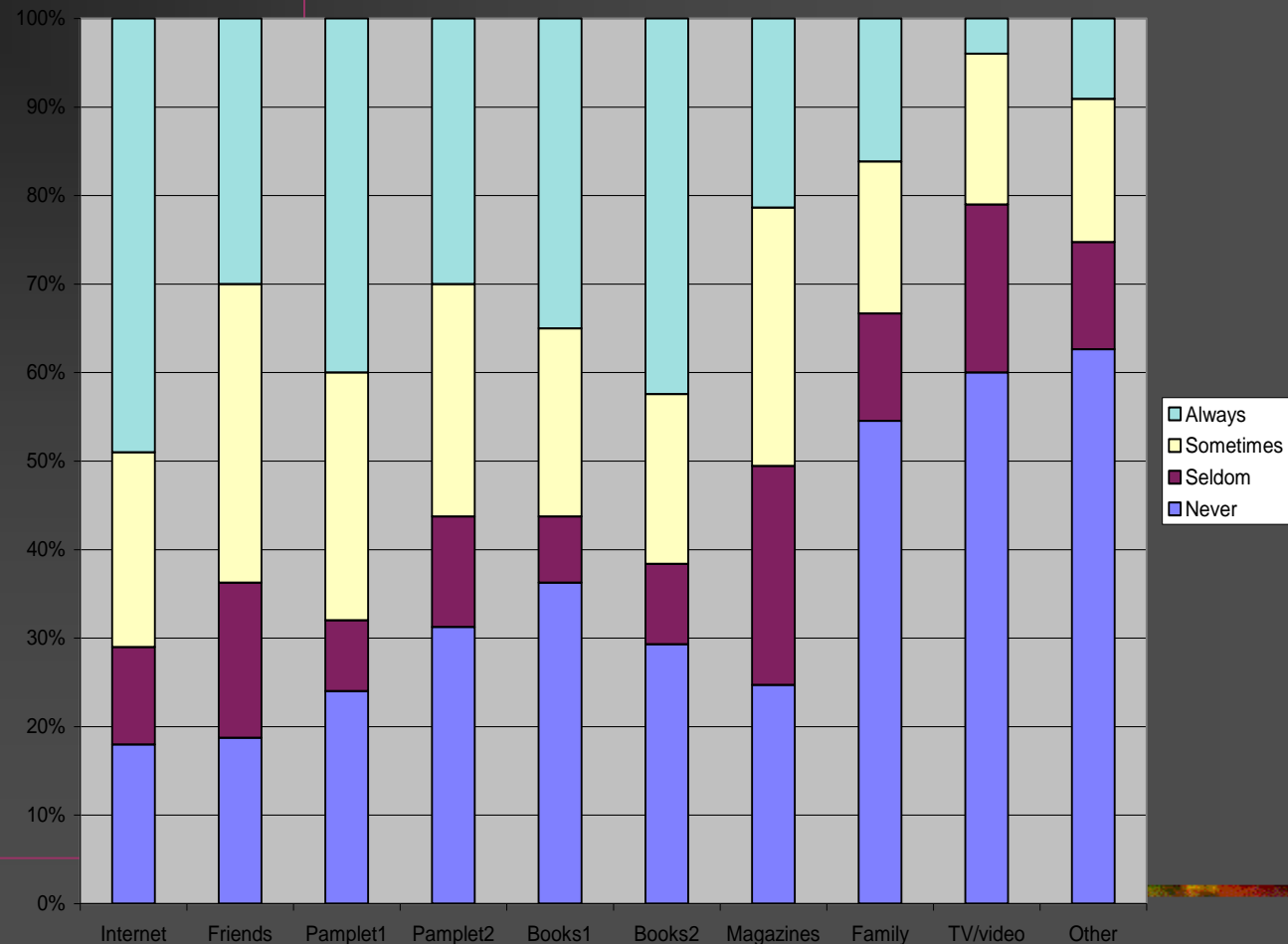
Aim 3: Quantitative phase

- Sample
 - Men who “had a choice” were given the packet in the clinic immediately after the options review talk
 - Puget Sound area specialists
 - Surgeons and Radiation Oncologists
 - 260 questionnaire packets returned
 - Standard instruments for demographics, anxiety, symptoms, activity level, decisional control, satisfaction
 - New written instrument for **personal factors**
-

Information sources used after the options talk

Top 4

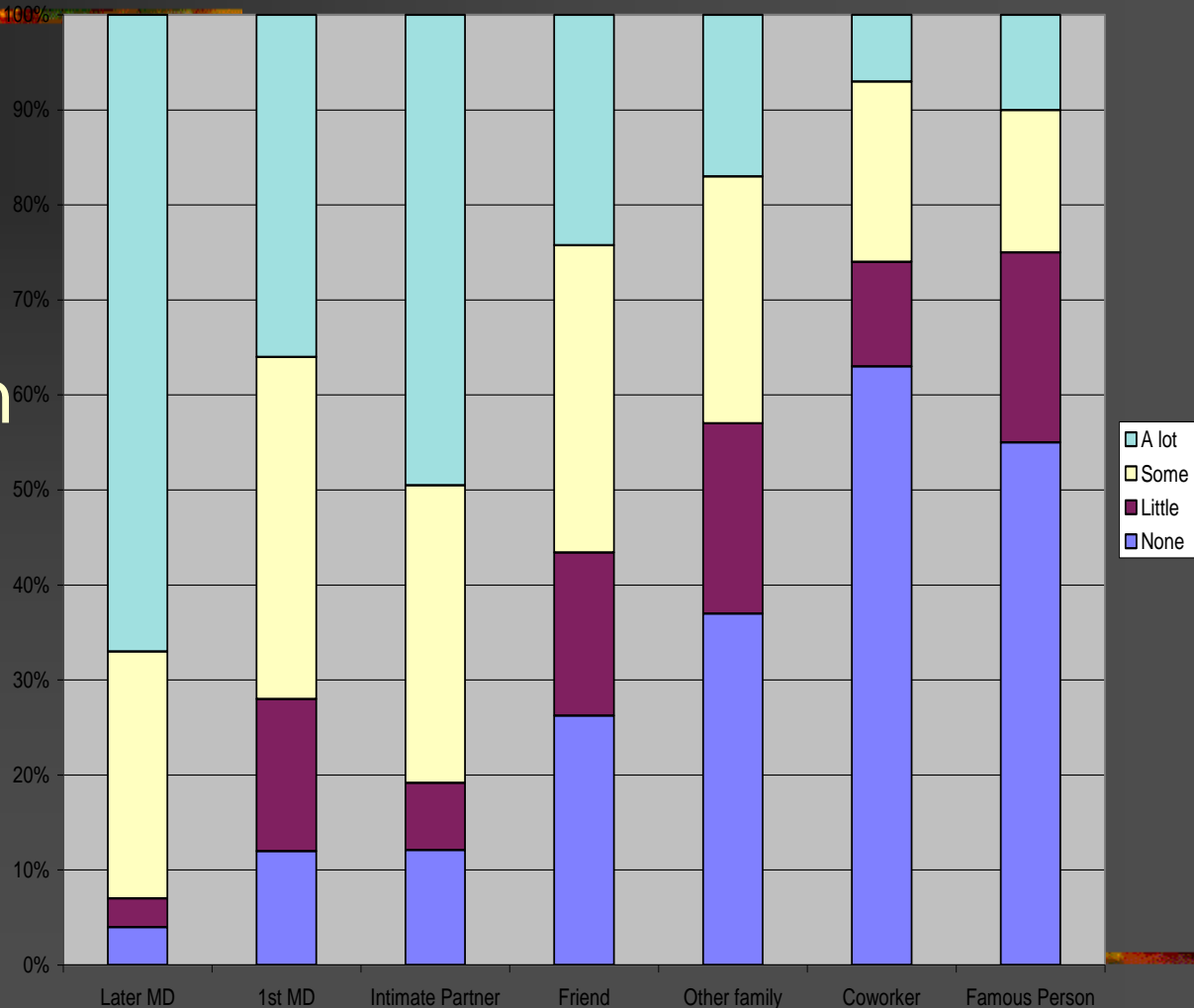
- Internet
- Friends
- Pamphlets
- Books



Influential people

Top 4

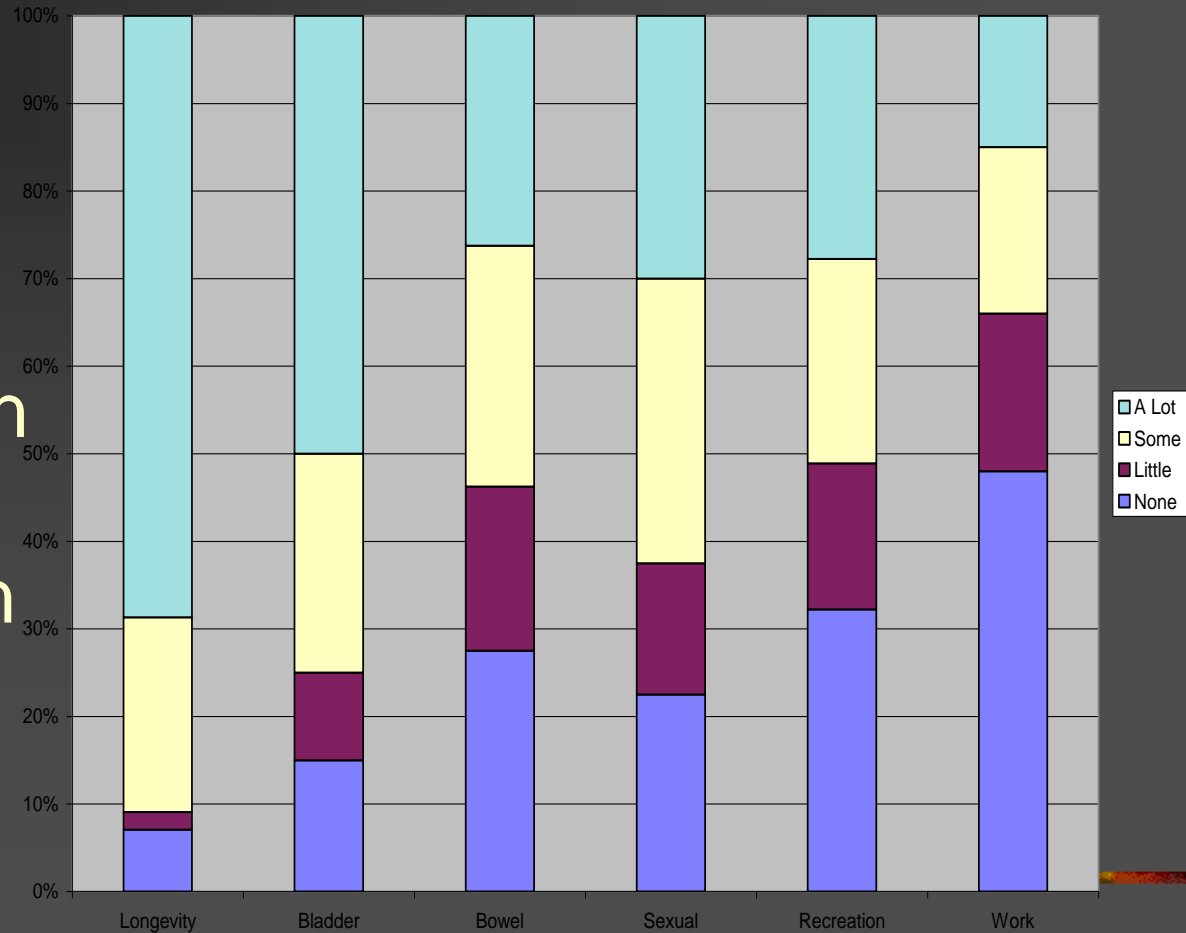
- .Second opinion doctor seen
 - .First doctor seen
 - .Spouse/partner
 - .Friends
-
- .Other family
 - .Co-worker



Influential outcomes

Top 4

- Longevity
- Urinary function
- Sexual function
- Bowel function



Final analysis of 'decision period' data

- Relationships between all variables and these two outcomes, **Satisfaction with Decision** (SWD) and **Treatment Choice**, (TC) were explored using exhaustive CHAID (Chi-squared Automatic Interaction Detector) in AnswerTree[®] 3.0 (SPSS[®], Chicago, IL).
- CHAID enables exploration of relationships through successive partitioning of variables with automated adjustment for the multiple partitioning.
- We entered 73 variables, including scale scores and individual items such as age.

Predictors: for those who had made a decision, n=224

- The strongest predictor partition variable for **SWD** was the subscale “factors contributing to **uncertainty**” (adj. $p < 0.0001$) followed by the **trait anxiety** score (adj. $p = 0.038$).
- The strongest predictive partition for the actual **TC** was **age group** (adj. $p < 0.0001$), followed by **marital status** (adj. $p = 0.0003$), influence of the first **urologist** seen (adj. $p = 0.0008$) and use of the **Internet** (adj. $p = 0.0479$).

What's this all about?

- **Homophily** (Lazarsfeld and Merton, 1964)
 - More communication between individuals that are alike, those that share common characteristics and beliefs
 - **Decision theories**
 - Yates Decision Theory
 - Social Network Theory
 - Complexity Theory
-

Conclusions

- Men with LPC were more satisfied with their treatment decision when they reported fewer uncertainty factors; mainly those factors relevant to information needed to understand the pros and cons and to make a decision.
- Consistent with this finding for TC is the use of the Internet
 - younger, partnered men who were more influenced by the surgeon and also those who used the Internet as an influential information source were less likely to have surgery.

Conclusions

- Overall, this study suggested that accurate information communicated to patients was of primary importance.
 - Personal factors were at play in the treatment decision and associated outcomes
 - Age appraisal and actual age
 - Anxiety
 - Intimate relationships
 - Shared decision control (MD influence)
 - Use of the Internet
 - Question! How could we facilitate the patient-report of personal factors and educate tailored to these priorities?
-

Personal Patient Profile – Prostate

Helping Men with New Prostate Cancer

Berry, Ellis, Lober, Davison, Blasko, Russell

I. R21 CA 10025

2003-2005

II. R01 NR 009692

2006-2009

Complete web-based system to teach and coach men as they prepare for the treatment decision

P4

P3P

Application

■ LAMP

- The Web application was implemented using PHP language
 - MySQL database on a Linux/Apache server,
 - All user interface components were implemented as dynamic server-side pages.
 - Surveys were presented using templates, making it simple to adapt the system to conform to user interface guidelines and to a variety of device characteristics
-

Personal Patient Profile-Prostate P3P



Personal Patient Profile - Prostate

Are you Spanish, Hispanic, Latino?

Yes
 No

What is your race? (Select one or more)

White, Caucasian
 Black or African American
 Asian
 American Indian, Native Alaskan
 Native Hawaiian or Other Pacific Islander

Personal Patient Profile - Prostate

How much influence might the following people have as you consider your treatment choice?

Your spouse or partner

No influence
 A little influence
 Some influence
 A lot of influence

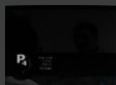
Personal Patient Profile - Prostate

How would you rate each of the following during the last 4 weeks?

Your ability to have an erection?

Your ability to reach orgasm (climax)?

Very Poor to None, Poor, Fair, Good, Very Good



Personal Patient Profile - Prostate

Based on what you said earlier, the following factors are important to you. Touch or click the buttons to see more information about each.

Influential people

Partner

Other influential factors

Recreation
Work

Influential outcomes

Bladder Function
Bowel Function
Sexual Function
Years to live

Current symptoms

Sexual
Bladder
Bowel

Personal Patient Profile - Prostate

It is always important to know what is meant by impotence when someone is speaking about it or when you read about it. You should also know that several factors influence whether or not you would be able to have erections, your age, your ability to have erections before treatment and what kind of treatment you have.

For example, you are told that 40% of men who have a radical prostatectomy, or surgical removal of the prostate gland will be "impotent". That means that 40% of 100 men have this problem, in this case, all the time for the rest of their lives. It does not mean that 40% of the time they cannot have or maintain an erection. Here's a picture to help explain:

After surgery to remove the prostate gland 40 out of 100 (40%) will lose the ability to have erections for the rest of their lives.

The other 60 out of 100 men (60%) maintain the ability to have erections and to have intercourse at some point after surgery.

Personal Patient Profile - Prostate

Percent impotent: The number of men within a group of people who will experience a condition of not being able to have a possible erection. There are several ways to think of impotence. It can mean:

a. No erection at all.
b. Partial erection but not enough for penetration or intercourse.

P4 Personal Patient Profile

University of Washington
Seattle Cancer Care Alliance

STAGE (SPREAD AND EXTENT OF CANCER)

Doctors use numbers and letters to "stage" the prostate tumor, that is, to describe the spread and extent of the cancer.

At the time of diagnosis, your doctor will use information from the digital rectal exam (DRE), Prostate Specific Antigen (PSA) blood test, and biopsy to decide whether more tests are needed. These tests are needed to evaluate the spread and extent of the prostate cancer. Before treatment, a clinical stage is given to the prostate cancer based on all these tests. Your doctor may offer different treatment options depending on your stage of cancer. The most common tests that can be ordered are:

- Bone scan:** A special x-ray done to show whether cancer has spread to the bone. This test is usually done if the doctor suspects the tumor may have spread, or if T3-stage disease and symptoms, such as bone pain, are present.
- Clign x-rays:** To confirm results of bone scans.
- Computed tomography (CT) scan:** A computerized x-ray of the prostate and other nearby parts of the body. This test is done if the PSA is greater than 20 and/or if you are considering radiation therapy.
- Magnetic resonance imaging (MRI):** A computer and high-powered magnet produce a picture that shows the prostate and other nearby parts of the body. This test is done if the bone scan results are suspicious.

My clinical stage, according to my doctor, is _____

The TNM (Tumor, Node, Metastasis) Clinical Classification is the most common method of staging prostate cancer. The names of TNM stages below start with "T" for the primary tumor (T1, T2, T3, T4). A parentheses, you will see the older type of stage labels used for prostate cancer (A, B, C, D).

[My Home](#)[My Top Concerns](#)[Statistics](#)[My Decision Role](#)[More About Prostate Cancer](#)[What Do You Think?](#)

Click to see other approaches:

 [Decision Is Yours](#) [Decision Is Shared](#) [Decision Is Doctor's](#)

My Role in Making a Decision

Talk to your doctor about the role you feel comfortable taking in making a decision about your care. This will help your doctor understand what you want.

Based on your answers, your preferred way to make a decision about prostate cancer care is shown below. You can also learn about other ways of making a decision by clicking on the links to the left to watch other videos.

DECISION IS SHARED

Your preferred way to make a decision about prostate cancer care:

I prefer that my doctor(s) and I share the decision about which option is best.



Next Section: [More About Prostate Cancer](#) >



Decisional control coaching video



Components of the Intervention

- Taking part in the treatment decision
 - Driven by Decisional Control Scale
 - Top information topics –text/print-out
 - Driven by Information Priorities
 - Understanding statistics-text and graphic
 - Driven by most influential outcome
-

Components of the Intervention

- Influential people: text and video
 - Driven by most influential person
 - Influential outcomes: text and video
 - Driven by most influential outcomes
 - Current symptoms: text and video
 - Driven by symptom assessment
 - Other informational web sites: text and printout
-

Pilot study results

- High enrollment rate 30/33
 - All men completed entire P4 program within 45 minutes
 - High acceptability ratings
 - All participants watched the tailored video clip describing the identified decisional control preference; and seven men watched additional clips representing other control preferences.
 - Ten men viewed a video clip from the menu of personal factor results.
 - Statistics graphics found very useful
 - Verbal comments indicated need for more time
-

1st P3P RCT Multi-site Trial

- Seattle
 - UWMC/SCCA
 - VA
 - Seattle Prostate Institute
 - Philadelphia –FCCC
 - Augusta Georgia-Medical College of GA
 - San Antonio- Univ of TX and VA
-

1st P3P RCT Multi-site Trial

- The purpose was to test P4, an innovative measure of personal factors and a customized Internet decision-support system, in a geographically and racially diverse sample for its effect on decisional outcomes.
 - Hypothesis: We anticipate lower levels of decisional conflict in the intervention group plus higher perception of preparedness and higher levels of satisfaction with decision.
 - Sub-objectives include comparisons of decisional control shift, quality of life and resource utilization.
 - Hypothesis: We anticipate a greater shift in control preference towards shared or autonomous decision making from baseline to post-decision outcome measures and fewer pre-decision physician contacts in the intervention group.
-

P4 RCT Multi-site Trial

- 494 participants
 - Home users and clinic users
 - New developments
 - Study tracker
 - tailored clinical trial management system
 - Video clips customized to age and race and language
 - Professional actors
 - Low literacy/visual deficit alternative presentation
-

Results

■ Primary Outcome

- GEE analysis, adjusting for most baseline variables indicated a beneficial effect on decisional conflict (DCS); men receiving the P3P intervention reported significantly less conflict six months after the on-study consult visit.
- Uncertainty subscale; $p = .04$
- (Lack of) Values Clarity $p = .002$
- Study site was also a significant predictor of decisional conflict

■ **Secondary Analysis of site differences:**

- Baseline decisional uncertainty ($p=0.001$) and informed ($p=0.03$) subscales were significantly different across sites. Individual characteristics of participants were significantly different ($p<0.05$) between sites at baseline except for trait anxiety.
- Greater percentages of minority men were enrolled at the Seattle VA, Augusta GA and San Antonio sites.

Results

- Physician consult visits prior to enrollment, minority race/ethnicity, and use of clinic-provided books were significant predictors of perceived preparation for decision making (PrepDM) at 1-month.
- Prior Internet use and PrepDM significantly predicted 6-month decision satisfaction. Decisional regret was significantly predicted by demographics, anxiety, PrepDM score, and EPIC bowel domain score at 6-months.

Site differences

- In univariate analysis, minority race/ethnicity was associated with lower uncertainty at baseline.
- In multivariable analysis, we identified participant level factors that explained study site differences at baseline for the decisional uncertainty and values clarity subscales:
 - Higher conflict
 - whether the study program was accessed at home vs. in the clinic
 - state anxiety
 - Lower conflict
 - having a preferred treatment choice at study entry
 - number of doctors consulted pre-study
 - working
 - information source from the media or a health care provider, and perceived knowledge level.
- Minority race/ethnicity was no longer significant at baseline as other important and related variables predicted uncertainty, notably state anxiety and how much, from where and what type of information had already been gathered.

Special populations

- Customizing to race, ethnicity, language and low literacy based on qualitative work with African American men and Spanish-speaking men
 - Testing usability with eye-tracking and video in 20 African American and 20 Hispanic men as they prepare for a treatment decision
 - A-B versions
-

[My Home](#)[My Top Concerns](#)[Statistics](#)[My Decision Role](#)[More About Prostate Cancer](#)[What Do You Think?](#)

Click to see other topics:

Outcomes[✓ Years I Expect to Live](#)[✓ Bladder Function](#)[✓ Sexual Function](#)[✓ Bowel Function](#)**Lifestyle**[✓ Work or Occupation
Activities](#)[✓ Recreational Activities](#)**People**[✓ Spouse/Partner](#)[✓ Co-worker](#)[✓ Friend](#)[✓ Family Member](#)**Current Symptoms**[✓ Bladder](#)[✓ Sexual](#)[✓ Bowel](#)

My Top Concerns

Based on your answers, we've calculated which factors are most important to you. Start with the one below and use the links on the left to explore other areas.

Years I Expect to Live

Based on your answers, how long you expect to live (this is also called survival) is important to you as you decide on your prostate cancer care.

Age and other things that affect survival

Nearly all men with [localized prostate cancer](#) will live at least 10 years after their [diagnosis](#). They may die sooner for another reason, like accidents or other illnesses. In general, prostate cancer is a slow-growing cancer.

For men with a [low risk](#) of cancer spreading or returning, there is no proof that any one kind of care will help them live longer than another kind of care. For men with a [medium- to high-risk](#) cancer, studies show that removing or treating the cancer is better than only watching it.

The most important thing in the [risk](#) of your cancer growing or spreading is the [Gleason score](#) of your cancer. There is good research that says that this score will predict how soon a man's cancer will spread and how many years he will live. Your doctor will talk to you about your Gleason Score and risk of your cancer spreading or returning.

The way you feel about your own age now and how long you expect to live is important in choosing your prostate cancer care. Other diseases or illnesses you have, or that your family has, also can affect how long you expect to live.

TALK TO YOUR DOCTOR

Talk to your doctor about your age and how long you expect to live. For example, you might say:

"Doctor, I feel like a young man at ... (say your age) and like I've



What we've learned over the years

- Feasible and acceptable
- Men want access from home
- P3P reduced decisional conflict
 - Knowing enough to diminish uncertainty
 - Clarified men values
- Delivering P3P after 2nd consult too late
- Time to disseminate!

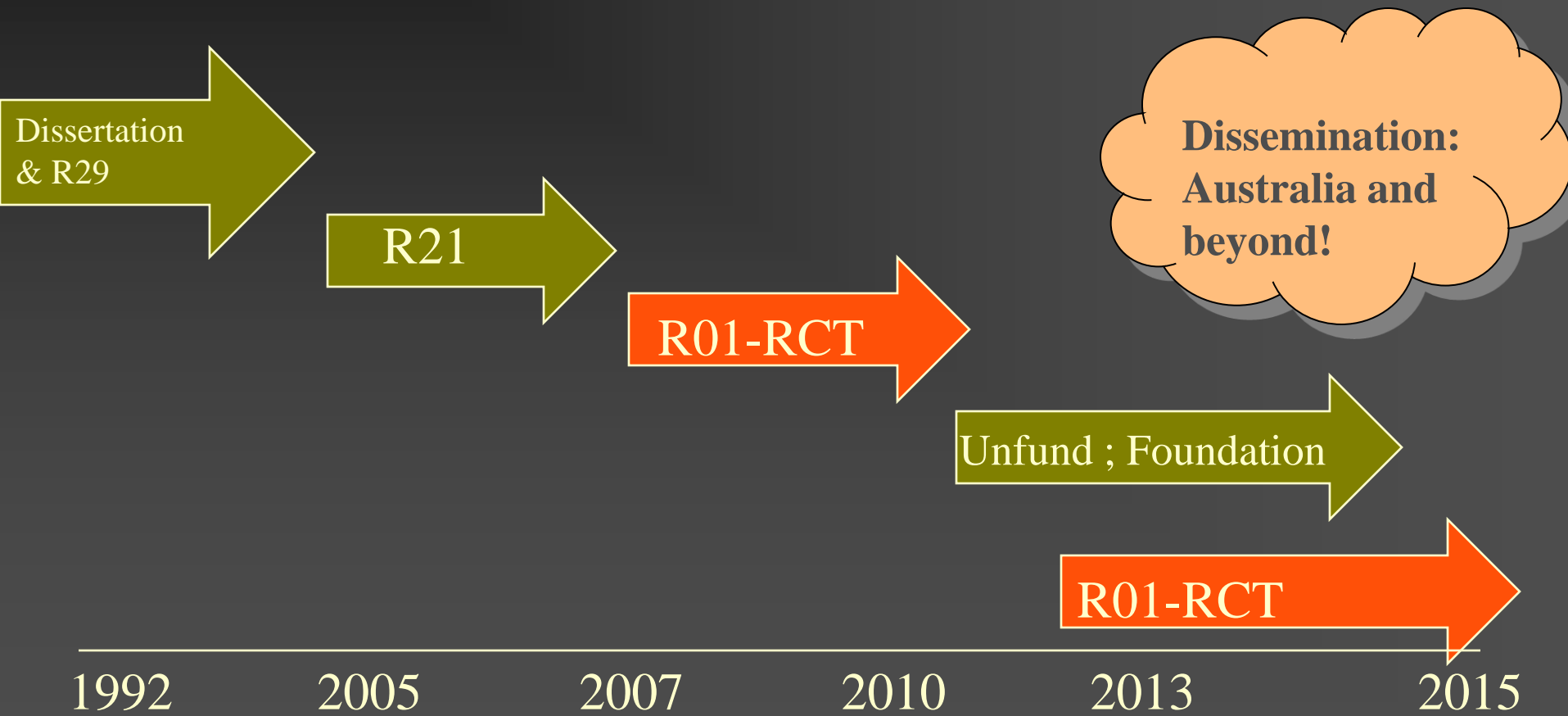
2nd P3P RCT-large health networks

- BIDMC, So CA Kaiser, Harris Hospital Districts, Emory Health, U Virginia
- Phase A randomized
 - Test new version for effectiveness
 - Cost -benefit analysis
- Phase B single arm
 - Evaluate implementation and sustainability as standard care

Technological challenge

- IRB required anonymous server entries until written consent
- When staff create a patient record, they only enter the appointment date.
- The patient record displays a unique url, along w/ instructions for staff:
 - "Highlight and copy the URL to use in an e-mail:"
 - The patient can use the url to log in until staff have entered PHI in their record, at which point it will redirect the patient to log in proper. That's the only limit: as long as that holds, the patient can do the assessments, view the intervention, etc.

A 22 year journey in decision support



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