

Writing health disparities research grants:

Tips from 3 decades of successful submissions

Rena J. Pasick

Éxito! & MTPCCR Webinar
September 12, 2017

❖ MTPCCR Alums:

Have you completed an alumni survey in the past two years?

Do we have your updated academic/career status?

MTPCCR Alumni Survey Link:

<https://redcap.ucsf.edu/surveys/?s=HWJK3L4JWY>

or contact

Vanessa.Mercado@ucsf.edu

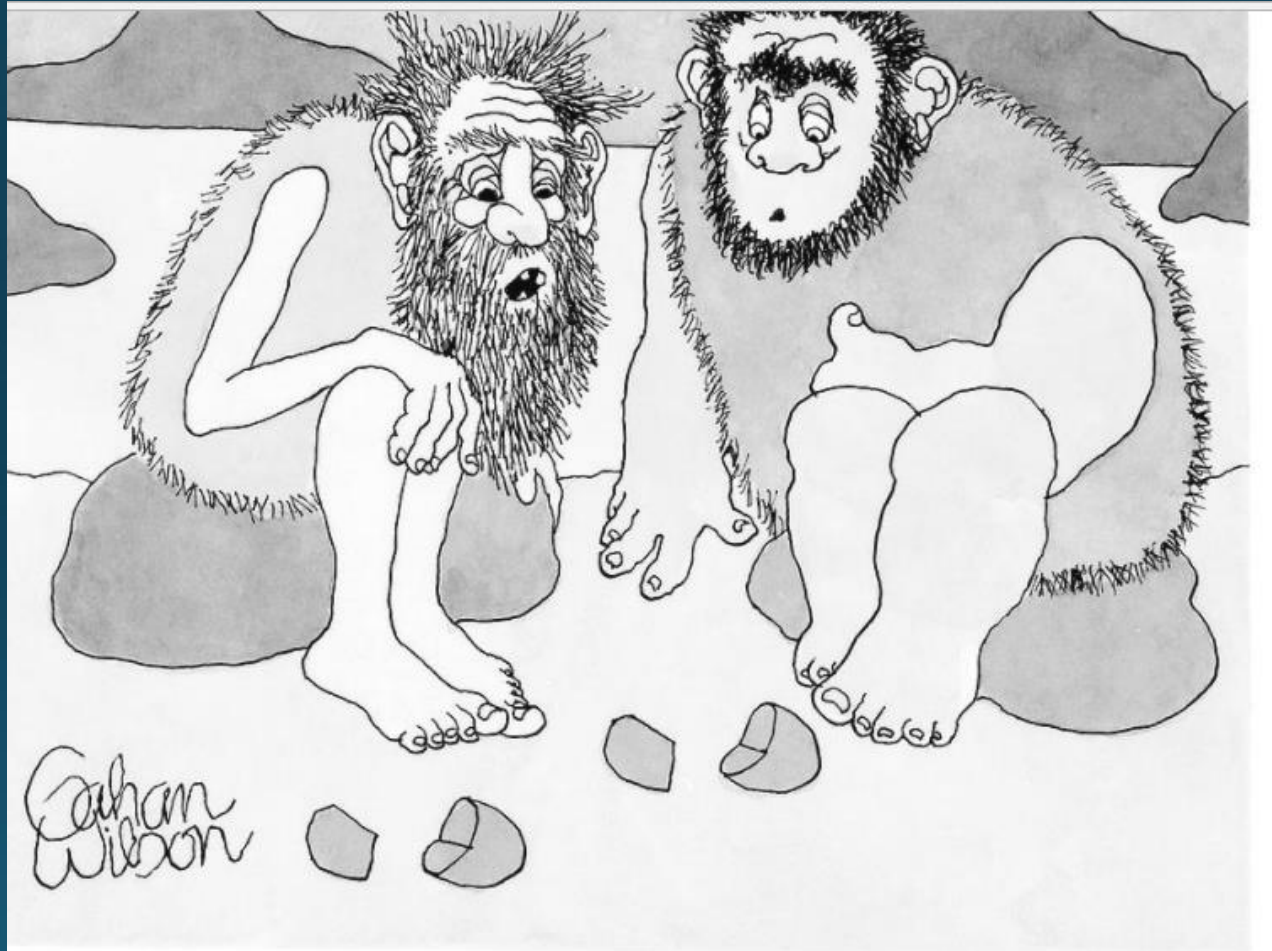


Grant Writing 101

On the menu

- The people who are key to your grant-writing success
 - your mentor(s)/formal and informal reviewers
- Tips (actually, more than Tips – MUST DO's)
 - research question/focus
 - striking the right balance: study scope
 - importance of page one
 - interesting reading vs YAWN
 - telling the whole story: bkgrd & prelim
 - culture: be explicit
 - methods: paint them a picture
 - methods, budget & budget justification
 - integrate theory throughout
 - style options that reviewers appreciate

Your Mentor(s)



“There—now I’ve taught you everything I know about splitting rocks.”

Reviewers -



Reviewers

- Don't expect familiarity with your specific area of research
 - Search for Study Section that is closest fit for you (eg Health Disparities and Equity Promotion Study Section – HDEP)
- Shocking but true: many reviewers just don't read each application carefully
- Junior reviewers tend to be far more critical than those with more experience

Plan for these worst case scenarios

Go

About CSR | Applicant Resources | Reviewer Resources | **Study Sections** | Rosters and Meetings | Employment

[Integrated Review Groups](#) | [Standing](#) | [Small Business and Technology Transfer](#) | [Fellowship](#) | [Special Emphasis](#)

Integrated Review Groups > **Healthcare Delivery and Methodologies IRG [HDM]** > Health Disparities and Equity Promotion Study Section [HDEP]

Health Disparities and Equity Promotion Study Section [HDEP] [+ Share](#) | [✉](#) | [🖨](#)

The Health Disparities and Equity Promotion (HDEP) Study Section reviews those applications where the primary aim is to address, reduce or eliminate health disparities and improve equity related to health risks, access to care, treatment, or health and health related outcomes. This study section reviews applications related to systematic influences/factors contributing to health disparities as well as those with a specific focus on health equity improvement in a particular sub-population or sub-populations of interest. The study section does not review basic science applications.

Rosters

HDEP Membership Roster

HDEP Meeting Roster

Topics

- » Studies where the primary aim is to address, reduce or eliminate health disparities and improve equitable conditions related to health risks and issues related to access to care and treatment faced by minorities and/or ethnic groups, LBGT, poor, homeless, rural, urban, low literacy, or immigrant populations.
- » Research with a focus on individual or microsystem level factors, including studies on potential mechanisms underlying health disparities and specific needs of disparity groups related to these mechanisms.
- » Studies related to the role of stigma in its relationship to health disparities or inequities in terms of health risks, access to care, treatment offered, and ways to promote equity and reduce or eliminate related health disparities/inequities.

Closely Related

Community Influences on Health Behavior [CIHB]
Community Level Health Promotion [CLHP]
Health Services Organization and Delivery [HSOD]
Clinical and Research Bioethics [CRE]

Policy Changes

- » Notice of Assistance Available to Institutions Impacted by Hurricane Harvey
- » Reminder: NIH Natural Disaster Policy - Hurricane Harvey
- » New Appendix Policy Related to Clinical Trial Applications Due on or After Jan. 25
- » NIH Continuous Submission Policy for Reviewers Updated
- » More ...

FAQs

- » For Applicants
- » For Reviewers

NIH
Center for Scientific Review

Health Disparities and Equity
Promotion Study Section
[HDEP]

- DO NOT contact study section members
- DO read their work
- Ok to write to SRO to ask which FOAs, PARs are reviewed by this group

<https://public.csr.nih.gov>

NIH Grant Review Process

https://public.csr.nih.gov/aboutcsr/contactcsr/pages/contactorvisitsrpages/nih-grant-review-process-youtube-videos.aspx

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NIH Peer Review Revealed

CSR has produced a series of videos to give you an inside look at how scientists from across the country review NIH grant applications for scientific and technical merit.

New and established applicants will find insights and understanding that can empower them to improve the applications and increase their chances for receiving a more positive review.

NIH Peer Review Revealed provides a front-row seat to a review peer review meeting.



Jumpstart Your Research Career with CSR's Early Career Reviewer Program tells how it works.



What Happens to Your NIH Grant Application shows our popular outreach talk.



NIH Tips for Applicants gives applicants practical advice and insights.



Policy Changes

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- » More ...

FAQs

- » For Applicants
- » For Reviewers

Familiarize yourself with the process

Volunteer to review small grants at your Institution

Ask more senior colleagues for grant reviews they have written

Reviewers:
give them what
they need

- You must live and breathe the review criteria
- Don't imply....STATE each one explicitly

- ✓ Overall Impact
- ✓ Significance
- ✓ Investigator(s)
- ✓ Innovation
- ✓ Approach
- ✓ Environment



*PAR & RFA: May add questions to each scored criterion or additional criteria

the ease and increasing use of this technology, and the fact that it represents a blend of some qualities of in-person with the potential for greater access. The last point relates to another important and unique feature of this research, our experience with and attention to the cultural context of the genetic counseling interaction.

As our own research has shown, *relational culture* (the processes of interdependence and interconnectedness among individuals and groups and the prioritization of these connections above virtually all else) is a powerful influence on health communication.⁸⁷ It is likely to figure prominently in our exploration of GC. In-person counseling offers the greatest potential for a meaningful trusting connection between patient and counselor, and video conference could function similarly. This can be highly significant among the cultures represented in our study but, as we have learned, not necessarily at a conscious level, in a way that can be readily articulated by the patient. Our methods are designed to elucidate these processes for a deeper understanding of the three counseling modes. The inductive multi-qualitative methods used in our above-cited study, like those proposed here, are also consistent with new recommendations recently released by the NIH Office of Behavioral and Social Science Research calling for more dynamic, contextualized understandings of culture and noting that “operationalizing culture usually does not lend itself to the identification of a predetermined battery of scales so common to research in the health related sciences. Inductive methods are required and mixed methods are

Innovation

- First safety net comparison of GC mode
- 3 arms/inclusion of video conference
- Preference and randomized groups
- Contextualized inductive approach
- Centrality of culture and health literacy

Note multiple dimensions/forms of innovation:
Research question, Method, Approach

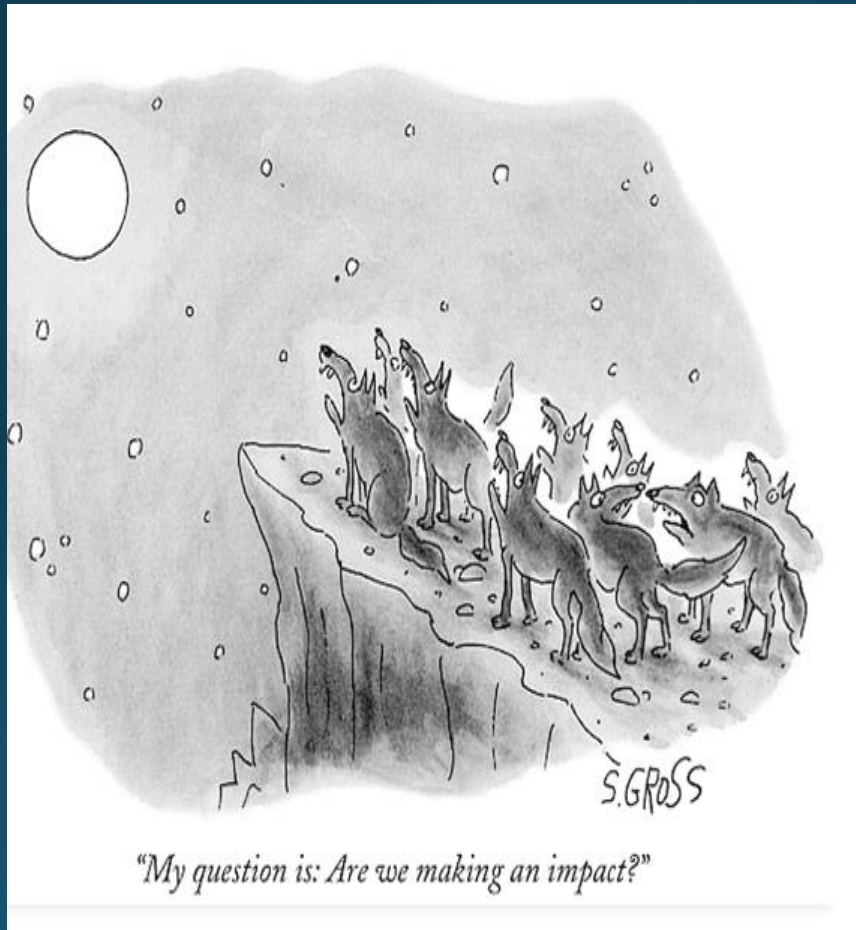
Research Question

Research Question

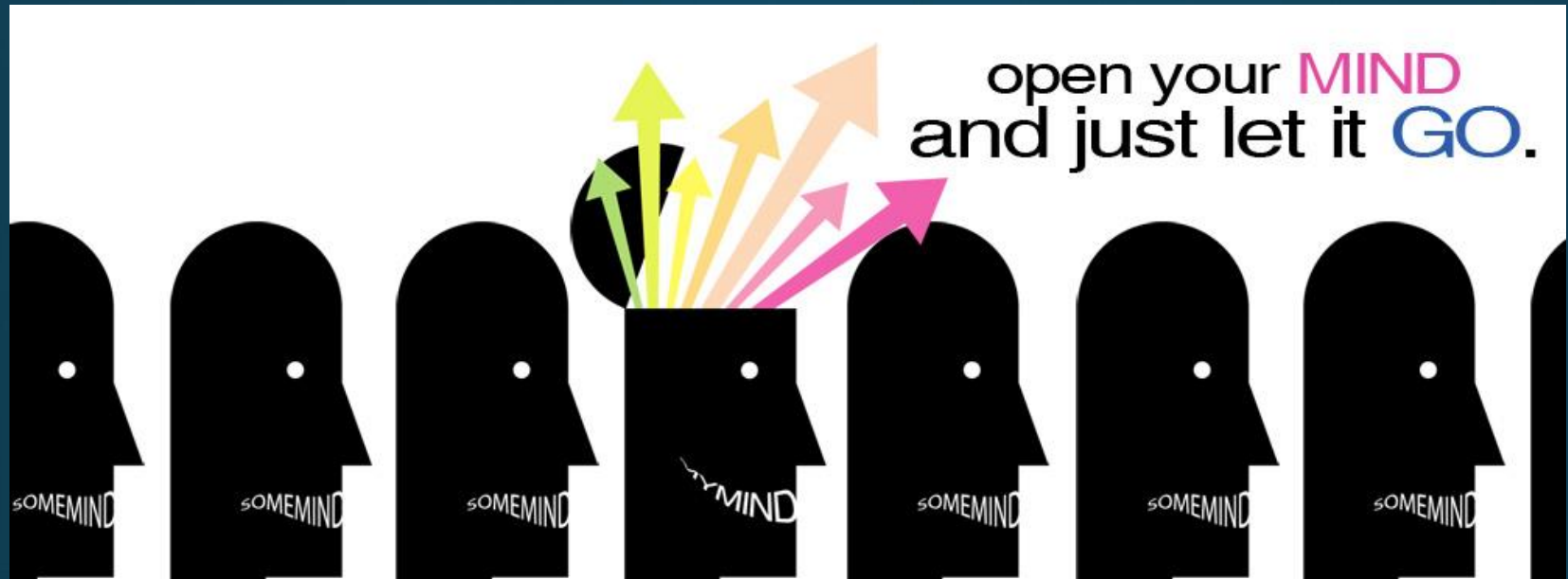
- Any **important** and **unexplored** question that **fits** your skills and budget
KEY: *Must demonstrate that all are true*
- Inductive or Deductive
 - Inductive/formative: explore largely unknown issue
 - Deductive: you or others have done sufficient prior research to inform your hypothesis test
- Intervention development and/or test of impact
- Methodological

NOTE: I have done *many studies that have no hypotheses*

Research Question



- Not just new – NOVEL
 - *How do you get to novel?*
 - Your interest +
 - A very new context*
 - and/or*
 - A very new approach*
- Open your mind
 - READ READ READ
 - Consult with many different people
 - Ask to see proposals
 - Ask to see Summary Statements
- Connect the dots



- ❖ Open your mind
- ❖ Read
- ❖ Consult
- ❖ Think CONNECTIONS
- ❖ Think INNOVATION

Read — lose yourself in the literature

- Latest top/relevant journals — to see current trends, all topics
- NIH Reporter - <https://report.nih.gov/>
- Funding mechanisms (R03s, R01s, R21s, etc.)
- Study section members' bios & pubs
- Google Scholar/PubMed (follow citation trails)
- Stay organized; keep files by topic; keep track of citations

*Now that you've done all this work,
publish a lit review*

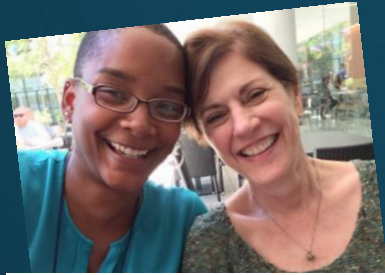


What's the connection?

Statewide toll free phone service referring women to free breast/cervical cancer screening



Research to recruit African American men for a prostate cancer prevention study



Constructing a Relational Bridge to Achieve High-Quality Prostate Cancer Care for African Americans

NCI Ko1 Grant to Nynikka Palmer, DrPH

SPECIFIC AIMS

High-quality cancer care occurs in a responsive health care system, where physicians practice patient-centered communication, and patients are informed and engaged.⁴⁶ In such a context, each patient can expect to receive the most appropriate treatment for his condition. This ideal, however, is often out of reach for one of the most marginalized groups in US society, African American men, particularly those experiencing the disproportionate burden of prostate cancer (PCa) borne by their community. African Americans have a 63% higher incidence, are more likely to be diagnosed with aggressive disease, and have more than twice the mortality due to PCa compared with White men.⁴⁷⁻⁴⁹ Among the causes of excess mortality is failure to receive definitive treatment (e.g., surgery and radiation) when it would be most beneficial (*under-treatment*).⁵⁰⁻⁵² In addition, *over-treatment* of low-risk disease (therapies that may not be beneficial yet have serious side effects) contributes to disparities in quality of life, as African American men report more treatment-related side effects that translate to lower quality of life.⁴⁹ All of these disparities are most pronounced among low income African American men, many of whom have low health literacy, and receive care in low resource settings (e.g., public hospitals and other safety net systems),⁵³⁻⁵⁶ where time constraints exacerbate communication barriers and degrade quality of care.

PCa treatment options present daunting communication challenges even for high literacy patients. There are complex trade-offs between survival and quality of life that are very personal. For example, men with low-risk PCa (which may never be life-threatening) can avoid invasive treatment if they are offered “active surveillance” (periodic biopsies and PSA tests). Patients considering this option need to fully grasp the fact that they have a cancer that does not require immediate treatment, but since the cancer can change, a protocol of repeat, uncomfortable procedures must be followed for many years. Opting for active treatment can result in impotence or incontinence. Patient comprehension of these issues is essential because only he can know

External validity/Real World

External validity/Real World

We propose a multi-level study¹² of prostate screening decision-making **in the real world where low-income men obtain care** including public health clinics and health fairs.

The strengths of our team include a cohesive committed coalition with close ties to community clinicians, and a multi-disciplinary group of community-oriented researchers from medicine (primary care, urology, and radiation oncology), social science (anthropology), and public health with established records in CBPR, mixed methods, and safety net setting health communication research.

Scope of the Study

Scope of the Study



- Consult – there will be many different opinions
- Most common error: biting off too much
 - Everything takes *longer* and *costs more* than expected
 - Experienced reviewers know this; inexperienced reviewers need to be convinced

Scope (con't)

- Map out all methods in excruciating detail
- Ascertain time needed to complete work
 - seek out advice from others with experience in the methods/context you propose
 - when in doubt, double the allotted time
- State explicitly how & why you developed the scope

Optimal Scope



Overarching/long-term research question/goal

Incremental steps addressed by the current study

Next steps

With the ultimate goal of increasing CRC screening among African American, Latino, and Vietnamese patients, the purpose of the proposed formative research is to develop and pilot test culturally appropriate guidelines and messages for use in a brief clinic intervention that will be implemented and evaluated in a subsequent study.

Connections

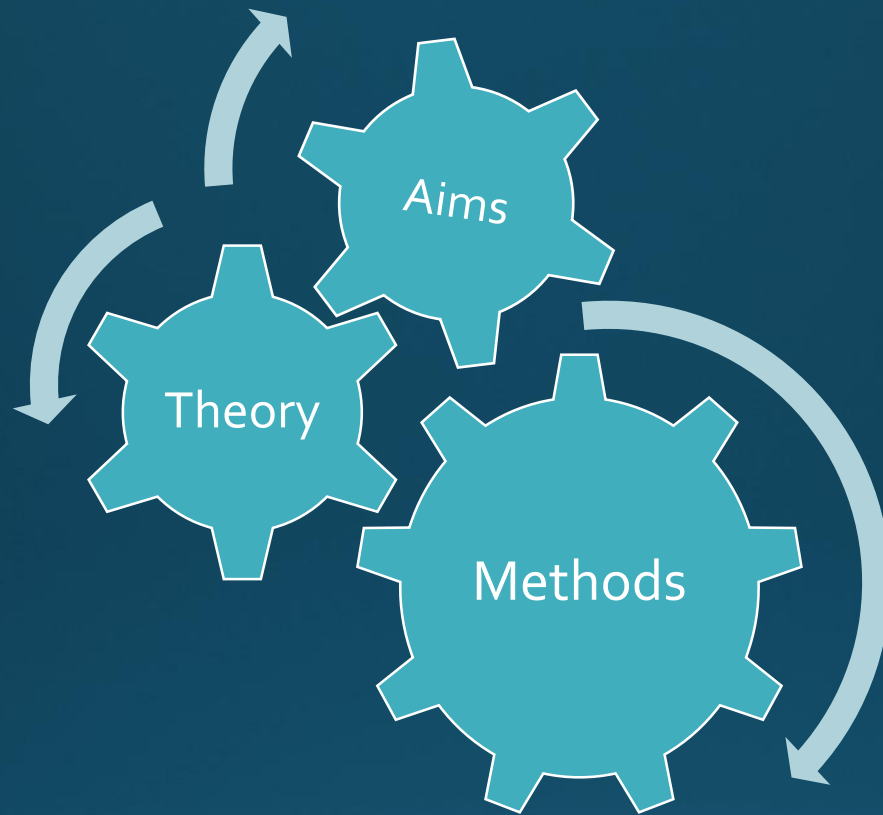
Connections



- Reviewers will not connect the dots
- Take them by hand; show them step by step

The proposed study is positioned at the intersection of **key gaps in the PCa disparities literature** and **the strengths of our research team**.

Gaps include sparse research on prostate screening SDM specific to both low-literacy men and to under-resourced settings where low-income men obtain screening. Examples of critical questions yet to be asked include: what really happens and what is possible regarding SDM in under-resourced settings? What is the meaning and potential of SDM for low literacy men? Is there an efficient alternative to the intensity of screening SDM when as much as 95% of tests end up normal (4.0 ng/mL).⁶⁰ Importantly, **most decision aids and communication toolkits address provider-patient communication in isolation from the setting where it occurs.**

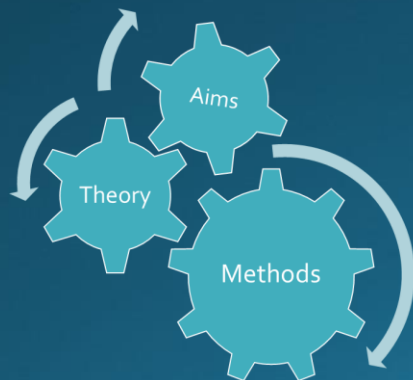


All components must be tightly interconnected

Including Budget, Timeline, Human Subjects

Make an “integration table”

| Aims | Conceptual Framework | Methods | Human Subjects | Team/Budget |
|--------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|-----------------------------------------|----------------------------------------------------------------------------------|
| 1. To document current practices in shared decision-making for PSA testing | Inductive Social context Health literacy Patient-centered communication | Mixed Methods Ethnography In-depth interviews Observations Web survey | Identical to methods – more elaboration | Team – all critical expertise represented Budget – every cost item identified |
| 2. To assess the feasibility of pre-biopsy counseling (PBC) for African American men | Adapt patient-centered communication functions and domains using “5As” model of behavior change | Observations Semi-structured interviews Phone surveys | | |



Background Pilot Data

- Focus groups with diverse public hospital cancer patients
 - 1 multi-ethnic English
 - 1 Spanish-speakers

Formative data showed that these patients
WOULD use the CIS if promoted to them
appropriately and if telephone protocols were
adapted specifically for them

Background Aims

- Increase use of the CIS through development of a kiosk serving as a direct link for public hospital cancer patients & families
- Adapt CIS by modification for literacy & development of proactive protocol
- Pilot test the kiosk and CIS protocol

Guide the
reviewer....
step by
step

Reviewers are not gazelles -
**do not expect
them to leap!**



Guiding the reviewer (con't)

- Nothing in the proposal should be *implied*
 - know what your assumptions are and spell them out
 - justify every statement of fact
 - with literature
 - with your preliminary data
 - Anything else **is an assumption** – which must be carefully, systematically justified

Cite Cite Cite Cite

- Any factual statement must be supported
- The more current, the better (classics are fine, but also show recent applications/developments)
- High quality journals/key researchers



Importance of first page

- Your relationship with the reviewer is established on

PAGE ONE

First page – not *just* the facts

Principal Investigator/Program Director (Last, First, Middle): Pasick, Rena J

Statewide Communication to Reach Diverse Low Income Women

There's a way to do it better - find it.

Everyone can relate to this

SPECIFIC AIMS

CHECK grammar!

Increasing interest and drama by changing up the sentence structure

Pushing the boundaries just a bit here

Best to end this paragraph with a key conclusion/ summary of your argument.

Recruitment of participants for clinical research and for prevention and early detection is always challenging. Recruitment from underserved communities can be particularly daunting and costly, particularly given the common practice of using an entire program as a recruitment strategy. It is a terrible irony that the inclusion of those who bear the greatest burden of disease, the poor, those less acculturated, and/or of low health literacy - is often associated with insurmountable challenges, time, effort, and frequently with limited success. This cycle is self-perpetuating. Marginalized populations have little access to medical care because systems are not designed for their needs; lack of community and institutional settings engenders distrust and further impedes use; and the complexity and meaning of cultural differences often elude researchers and practitioners. Thus, studies and services that might reduce suffering can actually create yet another disparity, failure to fully include those who could benefit most. This effect is magnified when the intervention is designed for individuals at high risk for life-threatening conditions such as breast cancer or chronic Hepatitis B infection.

First page (con't)

Compelling & succinct problem statement

The greatest burden of cancer, from incidence to stage at detection, survival and survivorship, is borne by populations described as “ethnic minorities” and “medically underserved.” These groups experience poorer access to medical care and typically do not receive the information, education, and support necessary for optimal health choices and successful navigation of complex treatment services. All cancer patients face a bewildering array of treatments, side effects, and emotions. Those who are underserved not only have few options for understanding and managing their illness, they are also underrepresented in the clinical trials that will ultimately yield the most promising treatments.

First page (con't)

Compelling & succinct case for the solution

The federal government's premier consumer health information program, the NCI's Cancer Information Service (CIS), offering the latest, most accurate information on cancer prevention, diagnosis and treatment directly to the lay public via a toll-free phone number, **should be a great resource for those most in need. But this is not yet the case.** While the race/ethnic distribution of callers to the California CIS for the year 2000 virtually matched that for California cancer patients in the same year, the education level of callers was much higher than that for the general population. **By virtue of its capacity, its mission, and emerging track record of novel and proactive services, the CIS clearly has the potential to serve a broader audience. The challenge is to find a mechanism that can put this valuable resource directly into the hands of underserved cancer patients.**

First page (con't)

The case for this study

Developments in health communication, coupled with advances in tailored multi-cultural communication from our own team, **can provide the missing link between the CIS and underserved cancer patients.** The **purpose of the proposed research is first,** development of a widely replicable health communication intervention that can bring the CIS directly to cancer patients in public hospitals. The **second purpose** is adaptation of CIS practices to enhance responsiveness to three critical needs of underserved cancer patients: information that is appropriate culturally and for varying literacy levels; assistance in communication with physicians; and information and encouragement regarding participation in clinical trials. **For such an intervention, formative research, and feasibility and efficacy testing precedes an effectiveness trial.**

Background & Prelim Studies should tell the *complete* story: why, how & who

- Background leads the reviewer from the problem to the solution
- Preliminary Studies shows why you/your team are ideally suited to conduct this study

Background & Prelim (con't)

- Background
 - use headings for each topic
 - make an outline for yourself
 - is the flow logical?
 - are there any gaps?
- Preliminary Studies
 - Headings by critical experience/skill

Background & Prelim (con't)

- Cancer disparities
- Info & support needs of low-income cancer patients
- CIS – underutilized by the underserved
- Forging a new communication link
- Effective communication with those of lower health literacy
- Effective communication across cultures
- CIS-Link: a three-fold focus
 - coaching for question-asking
 - information & completion of treatment
 - clinical trials
- Conceptual framework

(Some methods may require background too)

Background & Prelim (con't)

- Research on culture & communication
 - large scale studies of cancer outreach & communication (community & public hlth settings)
- Research based at the CIS
- Focus groups in preparation of this application
- (other) Formative research on culture & communication

(Biosketches should be fully consistent with Prelim Studies, but all critical points should appear in Prelim Studies or Budget Justification)

Key Elements

5. Methods: Paint them a picture

- Give a brief overview so reviewers know generally everything to come
 - summarize in a single paragraph
 - and/or use a graphic
 - phases are useful
 - ALWAYS tie to specific aims
- Then provide the details
 - every step, in excruciating detail



Table 1. Study Participants/Data Collection Methods/Objectives

| Participant/Event | n | Methods | Objectives |
|--------------------------------------------------------------------------------------------------------------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Aim 1. | | | |
| - Clinicians who conduct PSA tests at events or in clinics - Staff where testing is offered free or at low-cost | 20 20 | - Invite MDs/Nurse Practitioners and auxiliary staff to participate in semi-structured interviews (30 min for MDs, 45-60 min for other staff) | - Document usual communication with patients prior to PSA test - Address known facilitators/barriers to SDM - Explore specific features of the setting and patient population that affect current prostate screening communication practices - Elicit clinician's vision of optimal process/context and how this could be achieved |
| - Patients | 30 | - On-site intercept: Invite male Afr Am patients, ages 45-70, to participate in 45-60 minute semi-structured interview following receipt of PSA or decision not to obtain the test | - Assess patient's healthcare decision-making preferences - Assess understanding of PCa and the PSA test - Document communication that occurred with clinician or staff regarding receipt of the PSA - Assess comprehension and satisfaction with information obtained - Explore extent to which decision to test/not to test was consistent with patient's values |
| - Screening events or hlt h fairs where screening offered | 200 | - Record systematic observations of clinic procedures, interactions, and conversations in fieldnotes - Checklist for completeness/ consistency | - Document conversation topics; patient-provider rapport; question asking; whether provider checks for patient understanding; flow of conversation; if/how a testing decision is reached; immediate context e.g., patient or provider distraction |
| - Primary care clinicians | 150 | - Conduct 10-15 min structured web-based cross-sectional survey - Through the SF Bay CRN, recruit via email Bay Area primary care MDs with practices that include 10%+ African American patients | - Measure PSA test practices eg, proactively offer/only at patient request/conduct without offer; tailor by risk eg: Afr Am, family hx - Measure communication practices eg, standard approach (topics covered)/tailor to literacy, level of interest, questions/use of strategies to ascertain patient comprehension - Attitudes toward SDM/extent & nature of SDM practice; perceived barriers; satisfaction with skills - Measure degree of confidence in SDM skills - Information/training desired - Contextual factors (time, liability/ insurance considerations) |
| Aim 2. | | | |
| - African American men with elevated PSAs taking part in PPC | 40 | - Patients with elevated PSA - Patient attends counseling; session is audiotaped - Conduct 15-20 minute semi-structured | - Document patient participation rate (among those identified) - Post-counseling interview: Assess patient satisfaction, aspects that were helpful/not helpful, what was understood or unclear, confusing/intentions regarding follow-up/anticipated barriers and |

Methods – Conceptual Framework

- * Diagram not required!
- * Ok to blend various theories/constructs

D. Approach

Conceptual Framework. The backdrop for our study is the emerging theory of **Cultural Health Capital** (CHC – developed by co-mentor Dr. Shim) which elucidates the influence of fundamental social inequalities on clinical interactions, confounding patient-centered care and intensifying inequality.²⁶ CHC includes cultural skills, verbal and nonverbal competencies, attitudes, behaviors, and interactional styles that are valued, leveraged and exchanged by patients and physicians as they interact.²⁷

In this context, we employ Epstein and Street's model of Patient-Centered Cancer Care (PCCC)⁴⁶ for specific guidance in building **trust** and interactive **health literacy** (ability to use information). PCCC can improve survival and quality of life through i) activated patients, ii) responsive healthcare systems, and iii) communicative providers.

We posit that **cultivation of empowerment** is the key to bridging this gap, but that trust is a critical prerequisite. Thus, we propose a **relational intervention based on the cultural resource of brotherhood with AA PCa survivors as peer navigators**, to minimize the cultural and experiential differences that hinder patient-centered communication.⁸¹

Methods – Conceptual Framework

ii.) **Conceptual framework.** Our inductive ethnographic approach (described below), like grounded theory,³⁵ builds theory from data collected in the field rather than predetermining concepts and interactions. Following anthropologic tradition, we use broad conceptual frames to guide interpretation of our findings, particularly under Aim 1.

These include health literacy as a social determinant of health (the lifelong forces and processes that influence ability to use health information)^{36, 37} and social context as defined by Pasick and Burke (the sociocultural forces that shape people's day-to-day experiences).³⁸ Briefly, this means that we are looking for relationships and institutional conditions that elucidate health literacy and reveal its influence on communication and decision-making as well as strategies that enable SDM in the context of low health literacy.

For Aim 2, we will develop and test a counseling strategy that adapts "patient-centered communication functions and domains,"³⁹ operationalized in the "5As" model of behavior change (Assess, Advise, Agree, Assist, Arrange),⁴⁰ and Gaster's Ask-Tell-Ask approach²³ (see below, Counseling Protocol).

Methods, Budget, Budget Justification, & Human Subjects – *the iron triangle*

- Each and every action in the methods section must be matched to time, labor, and cost
- Every dollar in the budget should be associated with text in the Methods section and explained in the Justification
- Every point in the Justification should have budget and Methods counterparts

Iron triangle (con't)

- Inextricably linked – each offers a different way of explaining the study
- Keep the terminology **identical** (even in the timeline)
- Justification – err on the side of detail

(The Human Subjects section should also echo the details and terminology of the Methods section)

Integrate theory throughout

- The conceptual framework should flow logically
 - from the background
 - into the methods
 - measures
 - intervention elements
- It's ok to mix and match

Style Options

–avoid the yawn

- Keep text clean, inviting, easy on the eye
- Minimize bolding and underlining (*don't shout at me!*)
 - for emphasis, use a text box



II. RESEARCH STRATEGY

A. Significance

The excess burden of PCa borne by African American men should be treated as an urgent public health priority. Instead, early detection efforts have stalled in the face of questions regarding the mortality benefit of the PSA test and over-treatment of early stage disease following screening. Since the introduction of the PSA in the US, there has been a consistent decline of about 30% in PCa mortality overall,¹³ although the gap for African Americans persists.¹⁴ Statistical models have supported the role of PSA screening in the overall trend.¹⁵ While low-risk PCa has increased in the general US population, this is not true for low-income, uninsured men who consistently present with more advanced disease.^{16,17} Indeed, while the PSA debate focuses on the problems of over-diagnosis and overtreatment of men with screen-detected cancers, the greatest threats for low-income, uninsured men are under-detection and insufficient treatment.¹⁶

As the PSA debate continues, the universal emphasis on informed and shared decision-making has evolved with little regard for the implications for men of low health literacy or time-pressured and often chaotic health care delivery settings. The Institute of Medicine defines health literacy as "The degree to which individuals have the capacity to obtain,

1. IDM defined: the process patients go through to reach a healthcare decision by considering benefits, harms, risks; the match between these properties and personal values and preferences; understanding the uncertainty and limitations of a procedure.¹⁰

2. People with basic health literacy skills, (22% of US adults) can read and understand a short pamphlet explaining the importance of a screening test. They would not be able to reliably perform intermediate level tasks [eg use a chart to find the age when children should receive a particular vaccine.] Most would have difficulty understanding typical patient education handouts or filling in health insurance applications. (An additional 14% of adults perform below the basic skill level.)⁵⁴

process and understand basic health information and services needed to make appropriate health decisions.¹⁸ The definition of IDM (Box 1), when considered alongside a description of low health literacy (Box 2) reveals a deep chasm that poses yet another barrier to early detection of PCa in the highest risk groups. In fact, one study found African American PCa patients to be three times more likely to have low literacy skills than white men, and that men with low literacy skills were more than twice as likely to have a PSA level greater than 20 ng/mL at diagnosis compared with those of higher literacy.⁷ Indeed, in our community gatherings, men consistently ask "what is the prostate?" and "what does it do?"

The Centers for Disease Control has produced a brochure to assist African American men in IDM,⁶¹ but men of low literacy are less likely to attempt this process on their own. Yet the practicality of SDM as a standard of care, where clinicians

engage by eliciting patients' values and preferences, has not been established. Studies of the general population reveal a mix of appropriate and inadequate implementation of SDM guidelines for prostate screening.¹⁹⁻²³ Research specific to African American men and the few studies that address health literacy found greater barriers and inadequate SDM.²⁴⁻²⁷ Among the conclusions is that patients' ability to engage in SDM is determined by their literacy skills.²⁷ Thus far, research has not produced SDM strategies tailored for those who need it most: low-literacy African American men.²⁹⁻³⁰ To move beyond the current impasse, clinicians and policymakers need a clear understanding regarding if and how SDM can be used effectively with high-risk low-literacy men including identification of the optimal point in the early detection process for SDM.

B. Innovation

The novel features of this CBPR study include i) what is to our knowledge the first in-depth ethnographic exploration of prostate screening decision-making among low-literacy high-risk men in under-resourced settings; ii) development and feasibility testing of an approach to decision-making that shifts SDM from the multitudes who get screened to the few with elevated PSA levels; and iii) use of ancillary staff to reduce the time demands of SDM with low literacy patients for physicians. The use of an inductive approach and mixed methods, permitting examination of these issues from multiple perspectives, embeds this research in the real world of low income men and among the clinicians who provide their care. This is practice-based research, designed to emphasize external validity, the relevance and generalizability that enhance potential for translation into actual use.³¹ Finally, recognition of the multi-level nature of decision-making for PCa moves beyond the constraints imposed by data obtained only at the level of individual cognition, tapping influences

Text boxes

the role of PSA screening in the overall trend.¹⁵ While low-risk PCa has increased in the general US population, this is not true for low-income, uninsured men who consistently present with more advanced disease.^{16,17} Indeed, while the PSA debate focuses on the problems of over-diagnosis and overtreatment of men with screen-detected cancers, the greatest threats for low-income, uninsured men are under-detection and insufficient treatment.¹⁸

As the PSA debate continues, the universal emphasis on informed and shared decision-making has evolved with little regard for the implications for men of low health literacy or

time-pressured and often chaotic health care delivery settings. The Institute of Medicine defines health literacy as “The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”¹⁸ The definition of IDM (Box 1), when considered alongside a description of low health literacy (Box 2) reveals a deep chasm that poses yet another barrier to early detection of PCa in the highest risk groups. In fact, one study found African American PCa patients to be three times more likely to have low literacy skills than white men, and that men with low literacy skills were more than twice as likely to have a PSA level greater than 20 ng/mL at diagnosis compared with those of higher literacy.⁷ Indeed, in our community gatherings, men consistently ask “what is the prostate?” and “what does it do?”

The Centers for Disease Control has produced a brochure to assist African American men in IDM,⁶¹ but men of low literacy are less likely to attempt this process on their own. Yet the

1. IDM defined: *the process patients go through to reach a healthcare decision by considering benefits, harms, risks; the match between these properties and personal values and preferences; understanding the uncertainty and limitations of a procedure.*¹⁰

2. People with *basic health literacy skills*, *(22% of US adults) can read and understand a short pamphlet explaining the importance of a screening test. They would not be able to reliably perform intermediate level tasks [eg use a chart to find the age when children should receive a particular vaccine.] Most would have difficulty understanding typical patient education handouts or filling in health insurance applications. (An additional 14% of adults perform below the basic skill level.)*⁵⁴

Lastly....

- Err on the side of maniacal proof-reading
- Liberally reference other sections
- Repetition is key
- Anticipate and state limitations (but don't get too carried away)

Final Words

A proposal is never *finished* ...
It ends when you have to press “send”

❖ MTPCCR Alums:

Have you completed an alumni survey in the past one to two years?

Do we have your updated academic/career status?

MTPCCR Alumni Survey Link:

<https://redcap.ucsf.edu/surveys/?s=HWJK3L4JWY>

or contact

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