Engaging Underserved Patients in Health IT Design: A Technology-Enabled Prostate Cancer Decision Aid For African American Patients

RUTGERS

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Introduction

- PCa (Prostate Cancer) **mortality inequity** affects African American men (AAM)
- Black men make **different PCa treatment decisions** when compared to White men with similar risk.
- Use of PCa treatment decision aids (DA) can help **clarify priorities** and improve health literacy.
- Technology-enabled PCa treatment DA show increased shared decision making and health literacy, but minority patients are hindered because HIT tends to ignore social and cultural factors known to influence technology use.

Proposing a community-engagement approach involving AA PCa survivors in the design of a PCa treatment DA

Innovation

Minorities face barriers to technology use – Participatory Design (PD) can address barriers

- Technology enabled health promotion approaches tend to *ignore social and cultural factors* known to influence effective technology use which contribute to *intervention-generated inequality* – when interventions *disproportionally* benefit majority populations.
- Tools developed using participatory design (PD) can *abate* intervention-generated inequality, and *enhance* engagement, activation and health literacy.

Specific Aims

• Aim 1: <u>Modify a current tech-enabled</u> <u>decision aid (DA) via input from AAM PCa</u> <u>survivors and create prototype</u>:

Rationale – AAM PCa survivors have *particular insights* concerning what **health** *information* and *delivery* medium would help prepare AAM recently diagnosed with PCa for clinical visits. Training Goal: prototype development

• Aim 2: <u>Conduct a pilot RCT to assess</u> <u>acceptability, feasibility and preliminary</u> <u>efficacy of modified DA</u>:

Rationale – Use of a culturally-targeted DA will **better prepare** newly diagnosed AAM for clinical visits in which treatment options are discussed. **Outcomes** of interest: 1°- PCa knowledge, SDM (SDM-Q-9&-DOC - T0) 2° decisional perceptions (cancer-specific distress & anxiety). Training Goal: RCT design, cancer control

• Aim 3: <u>Assess effect on behavior during the</u> <u>clinical consultation:</u>

Rationale – Use of the DA will result in *increased shared decision making*, compared to usual care. **Outcomes** of interest: 1°- SDM (T1, T2-3mo.), Qual-OPTION Coding Scale), Training Goal: Patient-Clinician communication, SDM





Approach Tool refined and assessed using Participatory Design (PD)

- Stage 1: Exploration designers familiarize themselves with users and *understand* what information and mediums would support them. Initial step includes discussion of technologies, and information flows.
- Stage 2: Information Discovery designers and users *understand* and *prioritize* information. Enables designers to clarify users' goals and values. Usually involves several users.
- Stage 3: Assess designers and users iteratively *shape technology* to maximize usability and acceptability for circumstances detailed in Stage 2. Involves several users.

Stages are *iterated* several times, and provide an iterative *coexploration* by designers and users.

Approach also informed by health information seeking behavior (HISB)

- A health-threatening situation health circumstances influence type of information, amount of information sought, how the information is obtained, and when or under what circumstances the information is needed in order to help cope with stressful situations.
- 2. Participation and involvement in medical decision making –preferences range from *wanting to be able to understand* health care professionals' decisions about care, to wanting their *views to be heard and considered*, to actually *making* the final decision.
- 3. Behavior change and preventive behavior information can *influence* judgments, beliefs, and attitudes toward health behavior, the *alternative* courses of action known, and *risk perception* of certain actions and *resources* available to help carry out behaviors.

Expected Findings

- Tool *efficacy* will be evaluated based on: acceptability, usability, information received, and the following validated outcomes:
 - health literacy
 - patient "activation"
 - patient engagement
- Measure tool impact by *comparing outcomes* of experimental group with usual care – *50 AAM* recently diagnosed who have not used the tool.

Research Design

- Aim 1: Conduct 3 focus groups with 4 subgroups (1. AA PCa survivors, 2. AA at risk, 3. PCa survivor spouses/partners, 4. clinicians) for input on modifications to existing tool (Healing Choices for Men with Prostate Cancer).
- Aim 2: Conduct pilot RCT to assess the acceptability, feasibility and preliminary efficacy of the modified DA. 35 recently diagnosed AA use DA for 10 min within 5 days of clinical consultation, compare outcomes to usual care, 35 AA who have not used tool.
- Aim 3: Consultations will be audio recorded and coded to assess impact on SDM. Validated coding system will enable SDM measurement. Compare with "usual care".

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