

Patient Cancer OUtreach, Navigation, Technology and Support

Salma Shariff-Marco, PhD, MPH^{1,2,3}; Debora Oh, MSc, PhD^{1,3}; Tung Nguyen, MD^{1,2,4}; Janice Tsoh, PhD^{1,2,4}; Ching Wong¹; Laura Allen^{1,3}; Janet Chu, MD, MPH¹; Hoan Bui¹; Corina Liew¹; Angela Sun⁵; Joyce Cheng, MS⁵; Lei Chun Fung⁶; Scarlett Lin Gomez, PhD, MPH^{1,2,3}



¹University of California, San Francisco (UCSF), ²Helen Diller Family Comprehensive Cancer Center, ³UCSF DREAM Lab, ⁴Asian American Research Center on Health, ⁵Chinese Community Heath Resource Center. ⁶Chinatown Public Health Center.

INTRODUCTION

Background

- Cancer is the most common cause of death for Asian Americans.
- Many Asian American cancer patients do not receive appropriate treatment.

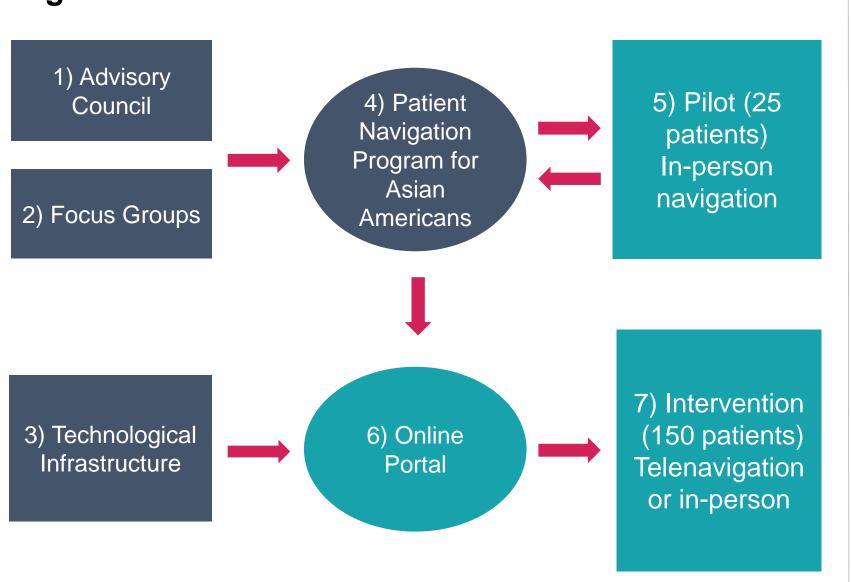
Vision

 The Patient COUNTS project will provide cancer patient and caregivers with accessible, culturallyrelevant, and linguistically-appropriate navigation resources that utilize technology to reduce disparities and improve quality of life.

Aims

- Identify Asian American adults newly diagnosed with colorectal, liver, or lung cancer using a population-based cancer registry;
- Conduct outreach to these patients to share information on these cancers, our web portal, and our patient navigation program; and
- Provide patient navigation virtually or in-person.

Figure 1. Patient COUNTS overview



1) ADVISORY COUNCIL

15 Advisory Council members (cancer patients, caregivers, navigators, and community partners)

- Recruited through community agencies, clinics, social networks, and referrals.
- 6 Languages spoken: English, Vietnamese, Mandarin, Cantonese, Taishanese, and Tagalog.
- 4 advisory council meetings.to date

Figure 2. Patient COUNTS logic model

People

• Staff

Family

Center

Health

Technology

OUTPUTS INPUTS OUTCOMES Activities Participation Short-term Long-term **Medium-term** Participants (patients Advisory • Identify issues regarding cancer care Program **Program** Program and caregivers) support for Asian Americans Improved patient Content for • Implementation in Council Advisory Council • Recruit 24-48 key informants and 25 portal for Asiancommunity and health navigation program patients for pilot study Americans care settings in CA Key components of **UCSF** resources • Feedback on program content Ability to build out to Adapting for other patient portal • UCSF Helen Diller • Identify key stakeholders and communities/ developed other languages, strategies for sustainability populations (e.g., geographies Comprehensive Cancer **Participant** Latino, African • Conduct 4-6 key informant focus Positive **Participant** American, rural) Focus groups • Greater Bay Area groups (with patients, caregivers, • Improved quality of user-experience Cancer Registry navigators, and providers) **Participant** Asian American Reduced disparities Research Center on • Train 2 navigators Pilot study in access to timely and • Implement 6-month navigation appropriate treatment Diverse eCohort Conduct evaluation Revise portal and navigation Patient portal • Develop patient portal in English, Patient portal • Eureka platform Chinese, and Vietnamese • Recruit 150 participants **SUSTAINABILITY** Implement portal and navigation Conduct evaluation Revise portal and navigation • Secure additional government and/or philanthropic funding • Build community and practitioner buy-in to continue the work Scale up • Expand program to serve other Asian • Conduct research that captures effectiveness of intervention American communities • Engage health system leaders to change practices • Continue to build out intervention • Disseminate findings and Patient COUNTS portal

2) FOCUS GROUPS

4 focus groups and 3 telephone interviews were conducted with a total of 17 participants in 4 languages (English, Cantonese, Mandarin, and Vietnamese). Preliminary results:

Information gathering

- Key sources were doctors, family, newspapers, websites, and WeChat groups.
- Information from reputable sources was valued; conflicting information led to distress.
- Those with limited income or English proficiency often did not know to ask for more information.

Emotional support

- Key sources were doctor, nurse or a hospital staff, friends and family.
- Was very important to provide encouragement to fight cancer.

Patient navigator (PN)

- Most were not familiar with term; once explained, most thought PNs were very desirable.
- Desirable characteristics included: empathy, caring, patience, resourceful, well-trained, language concordance.
- Most thought PNs did not have to be a cancer survivor or gender-concordant. Some preferred older PNs.

Navigation content

- Most wanted Information on symptoms and side effects and how to manage them.
- For technical terms, preferred both English and in-language words.
- Should include how families can participate in treatment decision making.
- Emotional and social support is most important.
- Should focus on the positives and provide information on sensitive topics (e.g., stigma, dying) only when asked; for end stage disease, provide information on palliative care and clinical trials.

3) TECHNOLOGY

Finalized platform for web portal (Salesforce). Proposed features include:

- Three languages (English, Chinese, Vietnamese)
- Tailored content for 3 cancer sites (colorectal liver, lung);
- Online eligibility screening, consenting, log-in
- Access to resources (social/emotional, financial, and logistical);
- Data collection and feedback:
- Educational videos; and
- Maintenance/scalability.

4) PATIENT NAVIGATION

- Developed navigation materials on:
 - Cancer information and treatment
 - Living with cancer
 - Emotional wellbeing
 - Resources (medical, financial, transportation, legal, housing, activities, child/adult care, cosmetics/DME, counseling, food and nutrition).
- Navigators attended 3-day training developed by collaborator.
- Developed surveys and needs assessment.
- Engaged recruitment sites.

NEXT STEPS

- Conduct pilot
- Develop online portal
- Implement intervention
- Continued planning for sustainability
- Health system mapping
- Partner action planning
- Partner engagement
- Data storytelling

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