

INTRODUCTION

Background

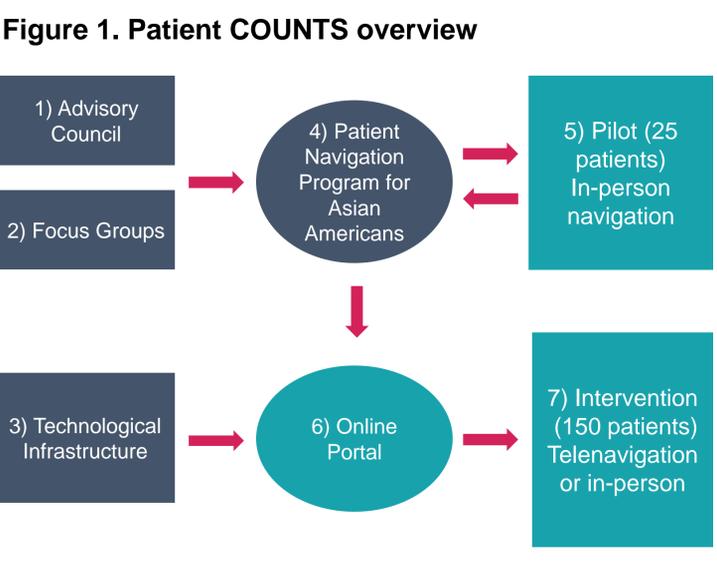
- Cancer is the most common cause of death for Asian Americans.
- Many Asian American cancer patients do not receive appropriate treatment.

Vision

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

Aims

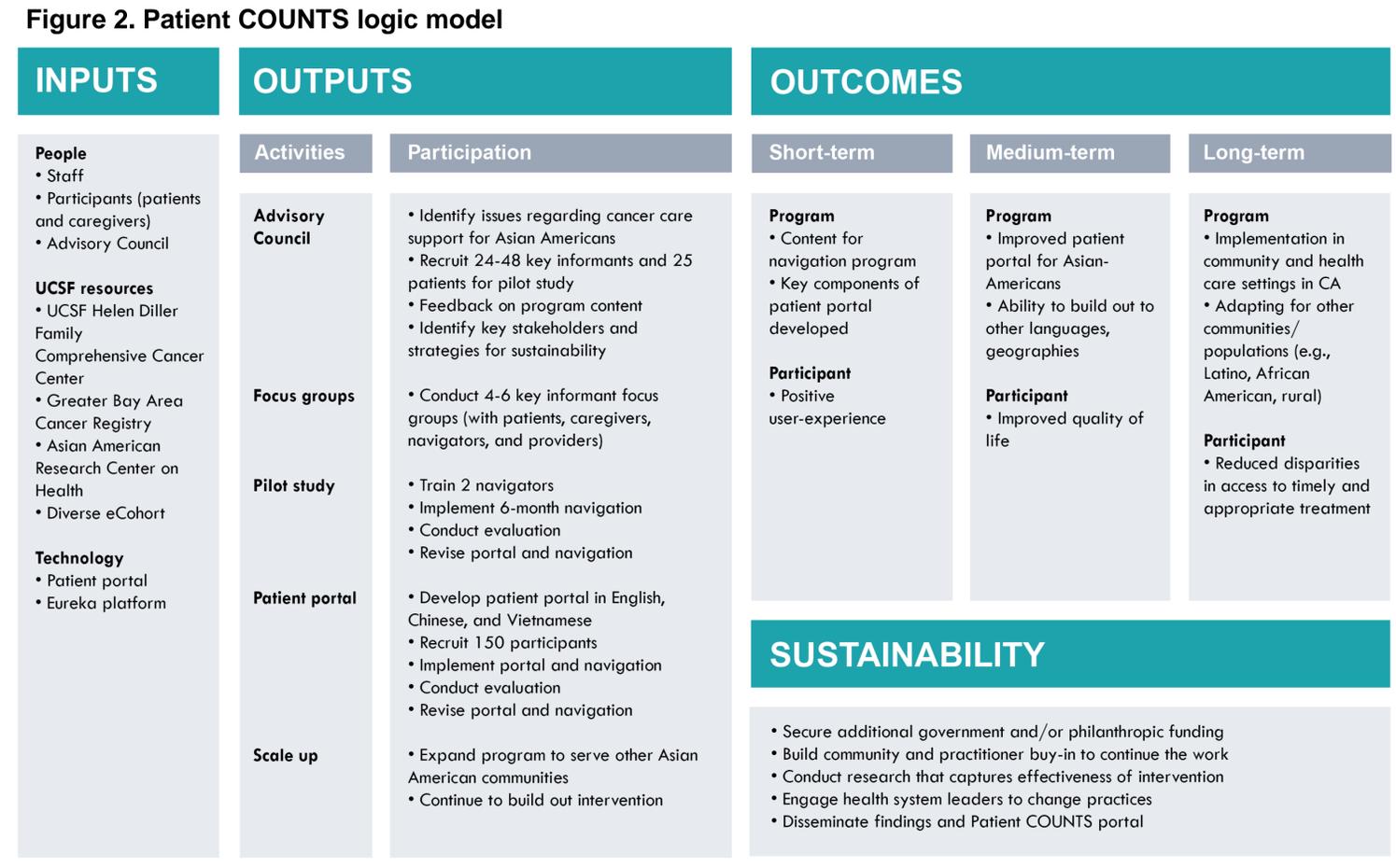
- Identify Asian American adults newly diagnosed with colorectal, liver, or lung cancer using a population-based cancer registry;
- Conduct outreach to these patients to share information on these cancers, our web portal, and our patient navigation program; and
- Provide patient navigation virtually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



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



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

Special thanks to the members of our advisory council: Anthony Nguyen, Jean Wang, Hoa Luong, Kong Chan, Lei-Chun Fung, Angela Sun, Tran Khanh Tuyet, ChoMei Johnson, Lily Tsen, Lillian Galedo, Thanh-Thuy Vo, Melida Bender, Thoa Nguyen, Melisa Wong, and Niharika Dixit.