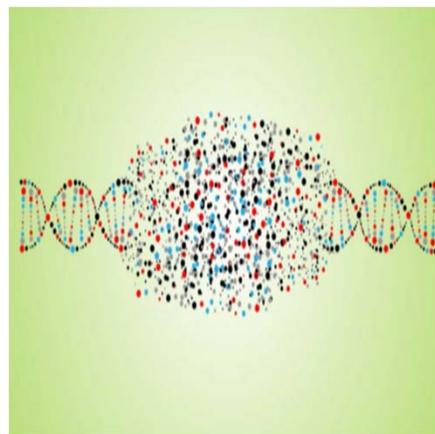




Exploring Innovative Solutions & Models of Success

Disparities & Access to Genomic Medicine



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Context

Access & Communication
are the bridge
connecting genetic
discoveries with
patients who will
benefit

Currently, those with the
greatest need have the
least opportunity to
receive the best care



Barriers on this
pathway will
INCREASE
cancer
disparities

+ Research Focus

In low resource
settings

Using inductive &
deductive paradigms

Qualitative &
quantitative methods

With multi-ethnic &
multi-lingual
populations

- Identify those at high risk for HBOC
 - among affected/unaffected
 - in clinic/community settings
- Innovate to improve access to/use of genetic counseling
 - via multiple channels
- Maximize effective communication
 - low health literacy
 - limited English proficiency

Study 1.

Statewide Communication to Reach High-Risk Low- SES Women

Pasick/NCI R01
2007-12



- Joseph et al, Pub Hlth Gen 2012
- Pasick et al, AJPB 2016

- RCT to ascertain whether low-income phone service callers would agree to family history screening, and if high risk, would obtain free genetic counseling. Interventions: immediate offer of GC app't vs receipt of brochure with instructions on how to obtain GC
- 709 (58%) of eligible callers completed brief FH screener ("6-Point Scale"); 99 (14%) were high risk
- Results: In all, 58% of high risk women were counseled; significantly more among the immediate appointment (38%) vs. brochure (5%) (p=0.0001).
 - These callers are "low-hanging fruit"
 - GC by phone was required for 54% of those counseled

Study 2.

Translating Cancer Genetics for the Safety Net Setting

Joseph/Susan G. Komen
2012-16



- Joseph et al., J Gen Couns 2017
- Cheng et al., J Comm Gen 2017
- Kamara et al., J Gen Couns 2017

- Ethnography of communication between genetic counselors and low-income English-, Spanish- and Cantonese-speaking patients in safety net settings to assess communication effectiveness from the patient's perspective.
- Observations/audio recording of 170 HBOC genetic counseling sessions/65 stimulated recall patient interviews; pilot test GC training in effective communication.
- Results: Serious mismatch between information provided and what patients wanted and could comprehend; more so using interpreters.

GCs knew they were not getting through and highly valued the training. Some strategies have proved challenging to put into practice.

Study 3.

Identification & Education of Low-Income Women at Risk for Hereditary Breast Cancer

Pasick/Susan G. Komen
2010-16

- Feasibility study of culturally tailored HBOC education in African American churches; main outcome: ID of high-risk women and their receipt of genetic counseling
- Participatory development of workshop curriculum & training of health ministry leaders; 41 workshops over 4 years generated 745 pre/post surveys and 729 family hx screeners
- Results: Successful refinement of key messages significantly raised post-workshop knowledge; overall, 84 high-risk women were identified and 50% obtained counseling.

Surprisingly, women who only filled out the family hx screener at Sunday Service were counseled at a higher rate than those who attended a 2-hour workshop



Stewart et al., Pub Hlth Gen 2016

Study 4.

Comparison of 3 Modes of Genetic Counseling in High-Risk Public Hospital Patients (GC3)

Pasick/NCI R01
2016-21

Do you have a family history of cancer?
We are looking for people to take part in a study on family history of cancer. If you are interested in participating, please complete this form.

This form is part of a research study conducted by your hospital and the University of California, San Francisco (UCSF). The purpose is to help patients with a family history of breast or ovarian cancer. If you are eligible for the study, we will call you with more information. We will be enrolled in the study ONLY if you are called AND you agree to participate.

Your Name: _____ **Age:** _____
E-mail: _____ **Today's Date:** _____
Cell phone: () _____ **Home phone:** () _____

Instructions: Please place an "X" in the boxes that describe you and your family.

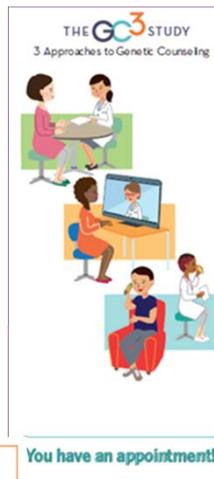
Your Family	No breast cancer history	Had breast cancer before age 50	Had breast cancer at age 50 or older	Had breast cancer at least twice
You	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your mother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your daughter(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grandmother (on mother's or father's side)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aunt(s) (on mother's or father's side)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sisters: 1 sister	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 sisters or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Have you had ovarian cancer (not uterine or cervical cancer)?
 YES NO or Don't know

Have any of your blood relatives had ovarian cancer (not uterine or cervical cancer)?
 YES NO or Don't know

Have any blood relatives had breast cancer?
 YES NO or Don't know

Have you ever talked to a genetic counselor about your personal or family history of cancer?
 YES NO



你有家族癌症病史嗎?
我們正在為一項有關家族癌症病史的研究徵集患者。如果您有興趣參加，請填寫此表格。

這份表格是研究的一部分，由您的醫院和加州大學聖佛蘭士哥分校（UCSF）共同進行。研究目的是幫助有乳腺癌或卵巢癌家族病史的患者。如果您符合研究資格，我們將與您聯繫。只有當您被聯繫並且同意參加時，您才會被納入研究。

個人資訊: 姓名: _____ 年齡: _____
 電子郵件: _____ 今天日期: _____
 手機號碼: () _____ 家庭電話: () _____

說明: 請在描述您和家人的表格中填上一個 "X"。

您的家人	沒有乳腺癌病史	50歲以前有乳腺癌	50歲以後有乳腺癌	至少兩次有乳腺癌
您	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
您的母親	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
您的女兒	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
祖母或外祖母	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
姑母或姨母(父方的姑姑)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
姊妹: 1個姊妹	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2個姊妹	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3個姊妹或以上	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

您是否有過卵巢癌(不是子宮癌或子宮頸癌)?
 有 沒有或不知道

您是否有任何血親曾患有卵巢癌(不是子宮癌或子宮頸癌)?
 有 沒有或不知道

您家裏有沒有任何成員患有乳腺癌?
 有 沒有或不知道

您曾經與遺傳諮詢師談過關於您個人和家裡的癌症病史嗎?
 有 沒有或不知道

- Genetic counseling is concentrated in academic centers; remote counseling is needed to reach low-income women - but little is known about the quality and effectiveness of remote counseling, particularly in the context of low health literacy and LEP
- Mixed methods RCT to compare in-person, phone, and video GC in 3 public hospitals; English-, Chinese- and Spanish-speaking patients. Target sample size: 540
- Process outcomes to date: a simple family hx form can be completed by patients in a variety of clinics
 - ~10,000 completed in 10 months
 - 634 (6.6%) potentially high-risk
 - 242 (38%) enrolled
 - 167 (69%) counseled
 - 144 (86%) completed follow-up survey



Progress



- Understanding the problems of reach, trust, communication
- Efficiencies in reach are achievable - but building trust and communicating effectively is very time- money- and labor-intensive
- Imperatives
 - Provide information and services to people where they are, with words they understand, and messages that are meaningful to them
 - All people and materials must meet these criterion
 - Train and retrain clinicians to avoid TMI, to use plain talk, and to check for comprehension

Remaining Challenges

- To achieve an educated public with participation from all sectors requires investment in innovative approaches and a much more diverse public health workforce
- Shortage of genetic counselors – and lack of diversity
- Policies to foster training of counselors and clinicians in effective communication
- Establish communication channels and partnerships between academic medical centers and safety net providers

A high-angle, wide shot of the Golden Gate Bridge in San Francisco. The bridge's iconic orange-red towers and suspension cables are prominent against a clear blue sky. The bridge spans across the blue-green waters of the Golden Gate Strait. In the background, the San Francisco city skyline is visible on the left, and rolling hills are on the right. The text "Thank You!" is overlaid in a large, black, serif font in the upper right quadrant.

Thank You!