A Traceback Cascade Screening Program in Ovarian Cancer

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Traceback Cascade Screening for BRCA 1/2

“A Traceback program could provide an important opportunity to reach families from racial, ethnic, and socioeconomic groups who historically have not sought or been offered genetic counseling and testing and thereby contribute to a reduction in health disparities in women with germline BRCA mutations.”

Traceback Cascade Screening Approach

Retrospective Proband Identification

Proband Testing

Cascade Testing

FACTS: Feasibility and Assessment of a Cascade Traceback Screening Program for Ovarian Cancer

Objective

• Determine the acceptability, feasibility, and effectiveness of a Traceback cascade screening program in multiple populations and healthcare systems to guide broader implementation

Research Question

• In what organizational contexts and populations a Traceback program for proband identification and cascade screening can be implemented, what would successful outcomes for such programs, and what are the contextual, logistical, and legal barriers to be addressed for such programs?
FACTS Study Aims

Evaluate Legal solutions through 50 state privacy law review and exploring HIPAA public health exception

Prepare culturally- and context- appropriate messages and delivery modes through stakeholder engagement

Pilot Traceback program in 3 health systems

Measure implementation outcomes
Implementation
Outcomes
Measured
Service
Outcomes
Measured*
Clinical / Health
Outcomes
Measured
*IOM Standards of Care

- Fidelity
- Reach
- Penetration

- Sustainability
- Costs

- Equity
- Effectiveness

- Patient-centeredness
- Timeliness

- Mutation status of probands
- Mutation status of relatives

- Participant satisfaction
- Provider satisfaction

How to Implement
Traceback Program
Explore HIPAA and other federal and state privacy laws for restrictions on contacting probands and family members

Stakeholder engagement for communicating to providers, probands, and family members about Traceback testing

Program to be Implemented
A Traceback cascade testing Program for previously untested women with ovarian cancer and their at-risk family members

Aim 1
Aim 2

Aim 3

Aim 4

Adapted from Proctor et al (2009)
Today’s Focus

Prepare culturally- and context-appropriate messages and delivery modes through stakeholder engagement

Human-centered design research methods to co-design a patient-centered process for probands and relatives at each of 3 health care systems
Participants chose:
• Up to five preferred statements (blue)
• Up to five not preferred statements (red)
• Up to five ambivalent statements (yellow)

Most only chose preferred statements
Preferred Modes activity

Participants “Chose their own adventure”

Participants given storyboard panels depicting different modes of receiving genetic testing information.

They built their “ideal experience” that would convince them to receive genetic testing.

Note: relatives had slightly different mode options. Probands received “Sam” storyboards, relatives received “Pat” storyboards.
Stakeholder Participants

- 70 interviews x 3 sites
  - 31 women with ovarian cancer
  - 39 family members (individuals with a relative with ovca)

- KPMAS – selected for Black race and within 1 year since diagnosis
- Geisinger – selected <5 years and >5 years post diagnosis; family members with a living relative, family members with a deceased relative
- KPWA - selected <5 years and >5 years post diagnosis

<table>
<thead>
<tr>
<th>Race</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Black or African American</td>
<td>10</td>
</tr>
<tr>
<td>White</td>
<td>54</td>
</tr>
<tr>
<td>Asian</td>
<td>5</td>
</tr>
<tr>
<td>More than one race</td>
<td>1</td>
</tr>
</tbody>
</table>
Why were top messages chosen?

We reviewed the comments participants made about why they chose the messages they did and summarized their reasons.
## Top Messages

<table>
<thead>
<tr>
<th>Testing Free to family members for 90 days</th>
<th>Ovca runs in families</th>
<th>GT identifies if risk increased / If + doctors have screening and prevention options</th>
<th>GT can help even if had ovca a long time ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Motivating especially for cost concerns</td>
<td>• New info, motivating</td>
<td>• Actionable and reassuring</td>
<td>• Emphasize science evolves over time</td>
</tr>
<tr>
<td>• Time limitation motivating (relatives)</td>
<td>• (relatives) scary or unrelatable – but important</td>
<td>• Offers next step (relatives)</td>
<td>• Motivating / actionable (proband)</td>
</tr>
</tbody>
</table>

GT: Genetic Testing
### Preferred Modes of Communication

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Targeted Communication</th>
<th>Passive Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Doctor in person</td>
<td>• Letter, portal, text</td>
<td>• Posters (waiting rooms, public)</td>
</tr>
<tr>
<td>• Doctor by phone</td>
<td>• Infographic, video, family letter (cascade)</td>
<td>• Ads (online, radio, TV)</td>
</tr>
</tbody>
</table>
G. Pat gets a phone call from their doctor’s office. A provider asks Pat to get genetic testing.

H. Pat’s doctor talks with Pat in person. The doctor asks Pat to get genetic testing.
Targeted messaging: communication sent to specific patients or relatives
Passive messaging: communication not sent to specific people

L. Pat sees a poster or graphic in a public space (mall, billboard).

K. Pat sees or hears an ad on TV, radio, or online. The person in the ad talks about who is at risk for ovarian cancer. The person also says how to find out if you are at risk.

F. Pat waits in the exam room. Pat sees the desktop screensaver. The screen shows facts about genetic testing for ovarian cancer risk.

E. Pat waits in the doctor’s waiting room. Pat sees a poster on the wall. The poster shows facts about genetic testing for ovarian cancer risk.
## Preferred Programs

<table>
<thead>
<tr>
<th>Alpha (Probands)</th>
<th>Alpha ( Relatives)</th>
<th>Beta ( Probands)</th>
<th>Gamma ( Probands)</th>
<th>Delta ( Relatives)</th>
<th>Epsilon ( Relatives)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor, then follow-up</td>
<td></td>
<td></td>
<td>Passive Communication, Doctor</td>
<td>Targeted Outreach, Doctor</td>
<td>Targeted and Passive Messaging, then Doctor Convos, some follow-up</td>
</tr>
<tr>
<td></td>
<td>Subgroup 1</td>
<td>Subgroup 1</td>
<td>Subgroup 1</td>
<td>Subgroup 2</td>
<td>Subgroup 1</td>
</tr>
<tr>
<td>Doctor, then Targeted and Passive Follow-up</td>
<td>Doctor, then Targeted and Passive Follow-up</td>
<td>Doctor, then Targeted Follow-up Only</td>
<td>Doctor, then Targeted and Passive Follow-up</td>
<td>Doctor, then Targeted Follow-up Only</td>
<td>Targeted and Passive Messaging, then Doctor Convos, then follow-up</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subgroup 2</td>
<td>Subgroup 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor, then Targeted and Passive Follow-up</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>GE Total</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>KPMA Total</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>KPWA Total</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>7</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>
Alpha: Clinician conversation, then follow-up

Probands and Relatives

Doctor conversation between provider and patient

<table>
<thead>
<tr>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Targeted messaging:</td>
</tr>
<tr>
<td>communication sent to</td>
</tr>
<tr>
<td>specific people</td>
</tr>
<tr>
<td>Passive messaging:</td>
</tr>
<tr>
<td>communication in a public</td>
</tr>
<tr>
<td>area (for some)</td>
</tr>
</tbody>
</table>

Preferred by participants at KPMAS and Geisinger
Beta: Passive outreach, clinician conversation, then targeted follow-up

<table>
<thead>
<tr>
<th>Doctor’s Office Messaging</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive messaging:</td>
<td>Targeted messaging:</td>
</tr>
<tr>
<td>communication in a</td>
<td>communication sent to</td>
</tr>
<tr>
<td>public area</td>
<td>specific people</td>
</tr>
<tr>
<td>Doctor conversation</td>
<td></td>
</tr>
<tr>
<td>between provider and</td>
<td></td>
</tr>
<tr>
<td>patient</td>
<td></td>
</tr>
</tbody>
</table>

Preferred by participants at KPWA
Gamma: Targeted outreach, clinician conversation, then passive follow-up

Probands

<table>
<thead>
<tr>
<th>Targeted Outreach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Targeted messaging: communication sent to specific people</td>
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</tbody>
</table>

Doctor conversation between provider and patient

👍 Acceptable to participants at all sites
Delta: Targeted and Passive Messaging, then clinician conversation

<table>
<thead>
<tr>
<th>Outreach</th>
<th>Doctor conversation between provider and patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive messaging: communication in a public area</td>
<td></td>
</tr>
<tr>
<td>Targeted messaging: communication sent to specific people</td>
<td></td>
</tr>
</tbody>
</table>

Preferred more by participants at Geisinger and KPWA than by KPMAS
Epsilon: Targeted and passive messaging, no clinician conversation

<table>
<thead>
<tr>
<th>Outreach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive messaging: communication in a public area</td>
</tr>
</tbody>
</table>

Preferred by one participant at each site
Next Steps

• We have designed the processes for each organization to start with
• We will review with the KPMAS CAB for feedback
• Anticipate beginning outreach in March
• Adjust as needed based on uptake and explore similarities and differences
• Additional qualitative interviews
  • What worked at each site and why
  • What works for different individuals and why (and what doesn’t and why not)
  • Barriers and facilitators talking with family members
Guidance for the Field

- Engage stakeholders and co-develop processes
- Utilize mixed-methods and qualitative to explore reasons and meaning behind preferences and expressed needs
- Measure implementation outcomes in addition to effectiveness of programs
- Utilize tools from implementation science to guide design, adaptation, outcomes
- Report effectiveness and implementation outcomes to facilitate learning across systems, projects, programs more efficiently
Thank you!

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