

A Traceback Cascade Screening Program in Ovarian Cancer

*Alanna Kulchak Rahm, PhD, MS, CGC
Geisinger*

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Traceback Cascade Screening for *BRCA 1/2*

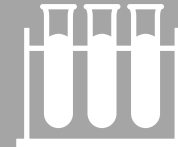
“A Traceback program could provide an important opportunity to reach families from racial, ethnic, and socioeconomic groups who historically have not sought or been offered genetic counseling and testing and thereby contribute to a reduction in health disparities in women with germline BRCA mutations.”

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?

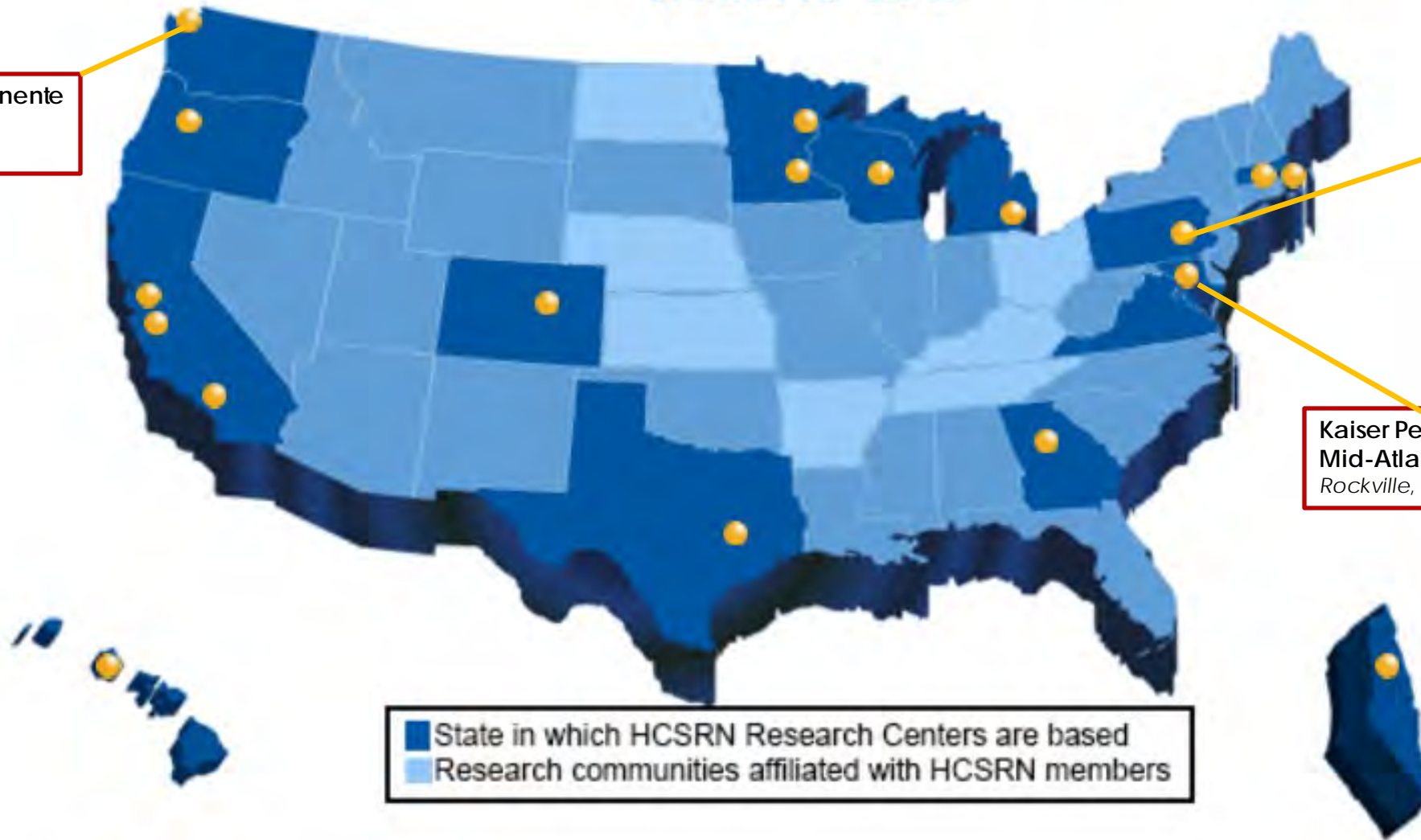
Health Care Systems Research Network Members



Kaiser Permanente
Washington
Seattle, WA



Geisinger
Danville, PA



■ State in which HCSRN Research Centers are based
■ Research communities affiliated with HCSRN members



Kaiser Permanente
Mid-Atlantic States
Rockville, MD



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

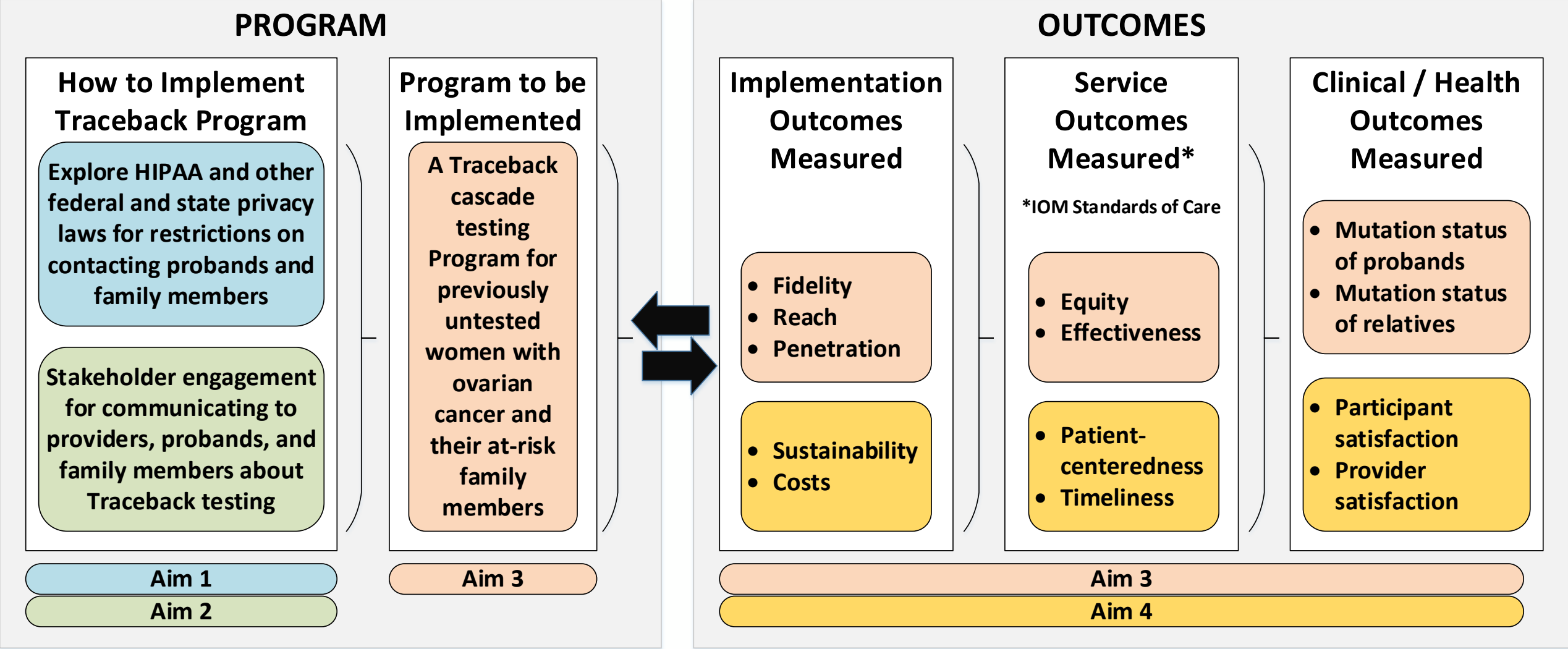


Pilot Traceback program in 3 health systems



Measure implementation outcomes

Figure 1. FACTS Study Conceptual Model: Based on the Conceptual Model of Implementation Research



Adapted from Proctor et al (2009)

Guiding Framework

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



Preferred Messages activity

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



1	Genetic testing can find gene variants (changes) that increase your risk of ovarian cancer.
2	Genetic testing is free to family members for 90 days after the ovarian cancer patient is tested.
3	If someone in your family ever had ovarian cancer, genetic testing can help other family members. It can help even if the person had ovarian cancer a long time ago.
4	Your privacy will be protected.
5	A genetic counselor can talk with you. The counselor can explain genetic testing and answer your questions.
6	People with ovarian cancer and their family members should get genetic testing. A genetic counselor can tell you which family members need genetic testing.
7	It is important that your family members get genetic testing also. This is important even if you do not get genetic testing.
8	Your risk is highest if your mother or sister with ovarian cancer has a genetic link (variant) that caused their cancer.
9	Ovarian cancer runs in families.
10	If you had genetic testing before 2014, you may need a newer genetic test.
11	When you get your genetic test results, a doctor may suggest your relatives also get genetic testing. This is called cascade testing.
12	Please talk with a genetic counselor. The genetic counselor can tell you if you need genetic testing.
13	If you have a mother or sister with ovarian cancer, this means you have a "family history" of ovarian cancer. Your chance of getting ovarian cancer is higher than the average person if you have this family history. About 5 in 100 women with family history will develop ovarian cancer during their life.
14	Ovarian cancer is severe.
15	If you have a genetic variant (change) that increases your ovarian cancer risk, doctors can help. You may be offered cancer screening or prevention options.

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.

A storyboard grid for 'Sam' showing various ways to receive genetic testing information. The grid includes 15 numbered panels with illustrations and descriptions of different communication modes like mail, text messages, doctor visits, patient portals, and video.

1. Sam's doctor talks with Sam in person. The doctor asks Sam to get genetic testing.

2. Sam logs into the patient portal. Sam finds a message from their provider. The message asks Sam to get genetic testing.

3. Sam watches a video about genetic testing for ovarian cancer risk.

4. Sam waits in the doctor's waiting room. Sam sees a poster on the wall. The poster shows facts about genetic testing for ovarian cancer.

5. Sam gets a letter in the mail. The letter asks Sam to get genetic testing.

6. Sam gets a text message from their doctor's office. The message asks Sam to please either call their provider or check the patient portal.

7. Sam waits in the exam room. Sam sees the desktop screen. The screen shows facts about genetic testing for ovarian cancer risk.

8. Sam gets an infographic in the mail. The infographic shows facts about genetic testing for ovarian cancer risk.

9. Sam gets a phone call from the doctor's office. A provider asks Sam to get genetic testing.

10. Sam schedules genetic testing

Stakeholder Participants

- 70 interviews x 3 sites

- 31 women with ovarian cancer

- 39 family members (individuals with a relative with ovca)

Race	
Black or African American	10
White	54
Asian	5
More than one race	1

- KPMAS – selected for Black race and within 1 year since diagnosis

- Geisinger – selected <5 years and >5years post diagnosis; family members with a living relative, family members with a deceased relative

- KPWA - selected <5 years and >5years post diagnosis

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

Testing Free to family members for 90 days

- Motivating especially for cost concerns
- Time limitation motivating (relatives)

Ovca runs in families

- New info, motivating
- (relatives) scary or unrelatable – but important

GT identifies if risk increased / If + doctors have screening and prevention options

- Actionable and reassuring
- Offers next step (relatives)

GT can help even if had ovca a long time ago

- Emphasize science evolves over time
- Motivating/ actionable (proband)

Preferred Modes of Communication

Clinician

- Doctor in person
- Doctor by phone

Targeted Communication

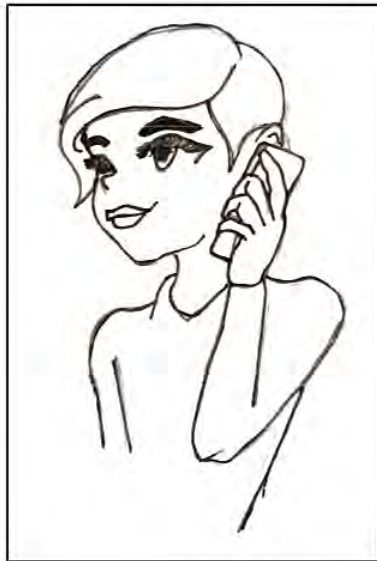
- Letter, portal, text
- Infographic, video, family letter (cascade)

Passive Communication

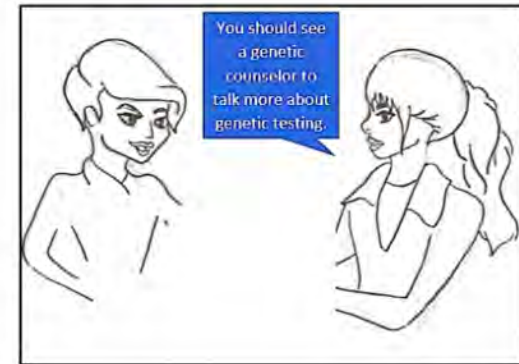
- Posters (waiting rooms, public)
- Ads (online, radio, TV)

Conversation with clinician

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.



J. Pat's genetic counselor gives Pat a letter. The letter is for Pat to give to their relatives. The letter asks the relatives to get genetic testing.



A. Pat gets an infographic in the mail. The infographic shows facts about genetic testing for ovarian cancer risk.



I. Pat gets a letter in the mail. The letter asks Pat to get genetic testing.



D. Pat gets a text message from their doctor's office. The message asks Pat to please either call their provider or check the patient portal.



C. Pat logs into the patient portal. Pat finds a message from their provider. The message asks Pat to get genetic testing.



B. Pat watches a video about genetic testing for ovarian cancer risk.



Targeted
messaging:
communication
sent to specific
patients or
relatives

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.



Passive messaging: communication not sent to specific people

Preferred Programs

	Alpha (Probands)		Alpha (Relatives)		Beta (Probands)	Gamma (Probands)	Delta (Relatives)		Epsilon (Relatives)
	Doctor, then follow-up				Passive Communication, Doctor Convo, then Targeted Follow-up	Targeted Outreach, Doctor Convo, some passive follow-up	Targeted and Passive Messaging, then Doctor Convo, some follow-up		Targeted and passive messaging, no doctor convo
	Subgroup 1	Subgroup 2	Subgroup 1	Subgroup 2			Subgroup 1	Subgroup 2	
	Doctor, then Targeted and Passive Follow-up	Doctor, then Targeted Follow-up Only	Doctor, then Targeted and Passive Follow-up	Doctor, then Targeted Follow-up Only			Targeted and Passive Messaging, then Doctor Convo	Targeted and Passive Messaging, then Doctor Convo, then follow-up	
GE Total	4	2	6	5	1	3	5	3	1
KPMA Total	3	5	1	3	1	2	1	2	1
KPWA Total	0	0	1	1	5	3	4	3	1
TOTAL	7	7	8	9	7	8	10	8	3

Alpha: Clinician conversation, then follow-up

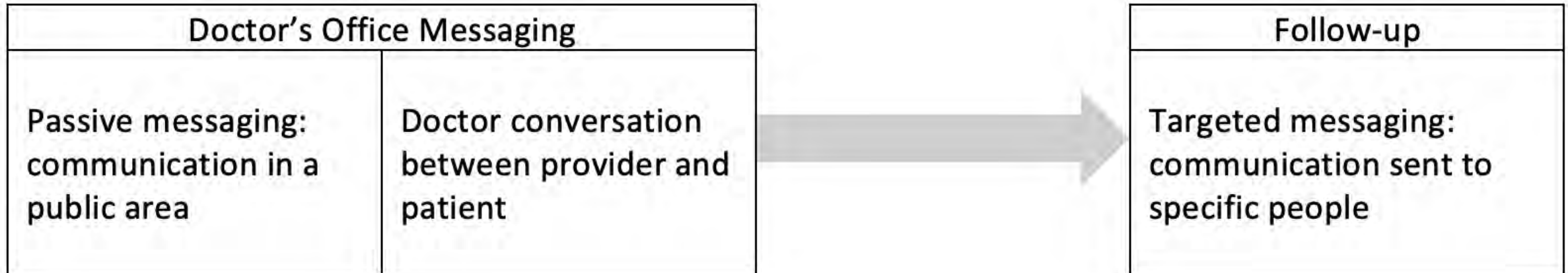
Probands and Relatives



Preferred by participants at KPMAS and Geisinger

Beta: Passive outreach, clinician conversation, then targeted follow-up

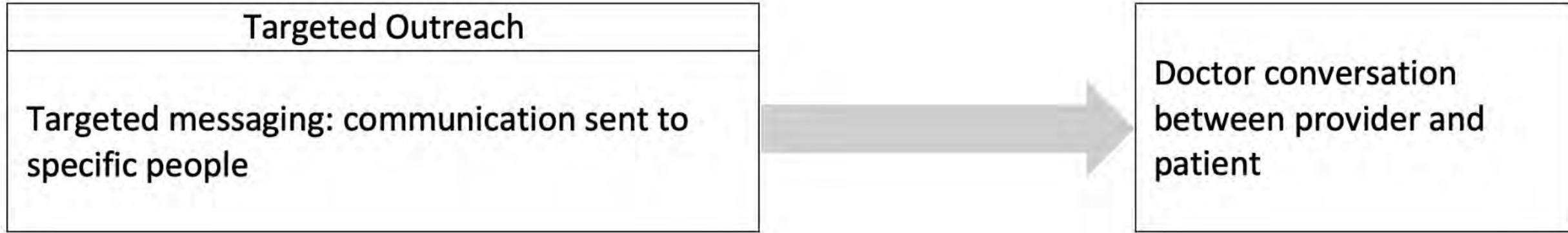
Probands



Preferred by participants at KPWA

Gamma: Targeted outreach, clinician conversation, then passive follow-up

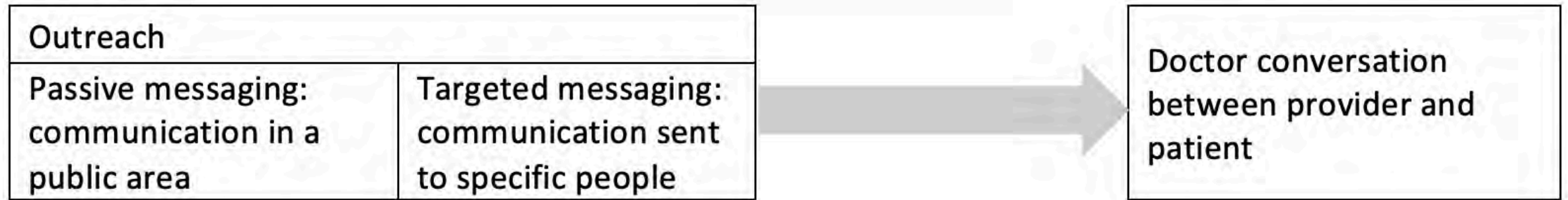
Probands



Acceptable to participants at all sites

Delta: Targeted and Passive Messaging, then clinician conversation

Relatives



Preferred more by participants at Geisinger and KPWA than by KPMAS

Epsilon: Targeted and passive messaging, no clinician conversation

Relatives

Outreach	
Passive messaging: communication in a public area	Targeted messaging: communication sent to specific people

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!

 akrahm@geisinger.edu



KP Mid Atlantic

Cabell Jonas
Pim Suwannarat
Maili Winther
Ashley Green
Anna Dinucci
Sundeep Basra
Jennifer Brown
Alex Kramer
Andrew Johnstone

G

Geisinger

Alanna Kulchak Rahm
Jing Hao
Yirui (Iris) Hu
Michelle Meyer
Jennifer Wagner
Katrina Romagnoli
Dina Hassen
Meredith Lewis
Steven Ney
Tracey Klinger
Ilene Ladd
Zachary Salvati
Rachel Schwiter



KP Washington

Nora Henrikson
Aaron Scrol
Paula Blasi
Kathy Leppig
Arvind Ramaprasan
Ken Kubota
Leigh Sheridan