Participant Needs, Diversity, and Equity

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Implementing and Evaluating Genomic Screening Programs in Health Care Systems—a Workshop

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Preferences for Genetic Testing to Identify Hereditary Colorectal Cancer: Perspectives of High-Risk Patients, Community Members, and Clinicians

Judith Walsh · Millie Arora · Christina Hosenfeld · Uri Ladabaum · Miriam Kuppermann · Sara J. Knight

- Patients and Public
  - Interest, willing to pay
  - Concern false negatives
  - Perceived health benefits of genetics
- Clinicians
  - Guideline focus
  - Concern about patient/family anxiety
  - Concern about downstream harms

Value of Genetic Testing for Hereditary Colorectal Cancer in a Probability-Based US Online Sample

Sara J. Knight, PhD, Ateesha F. Mohamed, MA, Deborah A. Marshall, PhD, Uri Ladabaum, MD, MS, Kathryn A. Phillips, PhD, Judith M. E. Walsh, MD, MPH

- Web-enabled survey, including a discrete choice experiment
- Probability-based online panel of US residents age 50 and older
- 355 participants completed the survey in April 2010

Predicted Uptake: Best test/Worst test

Improvement	Mean Predicted Uptake	Lower 95% CI	Upper 95% CI
Best test	97%	95%	99%
No test	3%	1%	5%
Worst test	41%	25%	57%
No test	59%	43%	75%

Best Results shared with primary care doctor
0% false negative

Worst Results shared with life and health insurance
20% false negative

Incorporating Genomics in Routine Care for Veterans with Colorectal Cancer

Retrospective cohort

How is genomic data incorporated into routine care of CRC patients

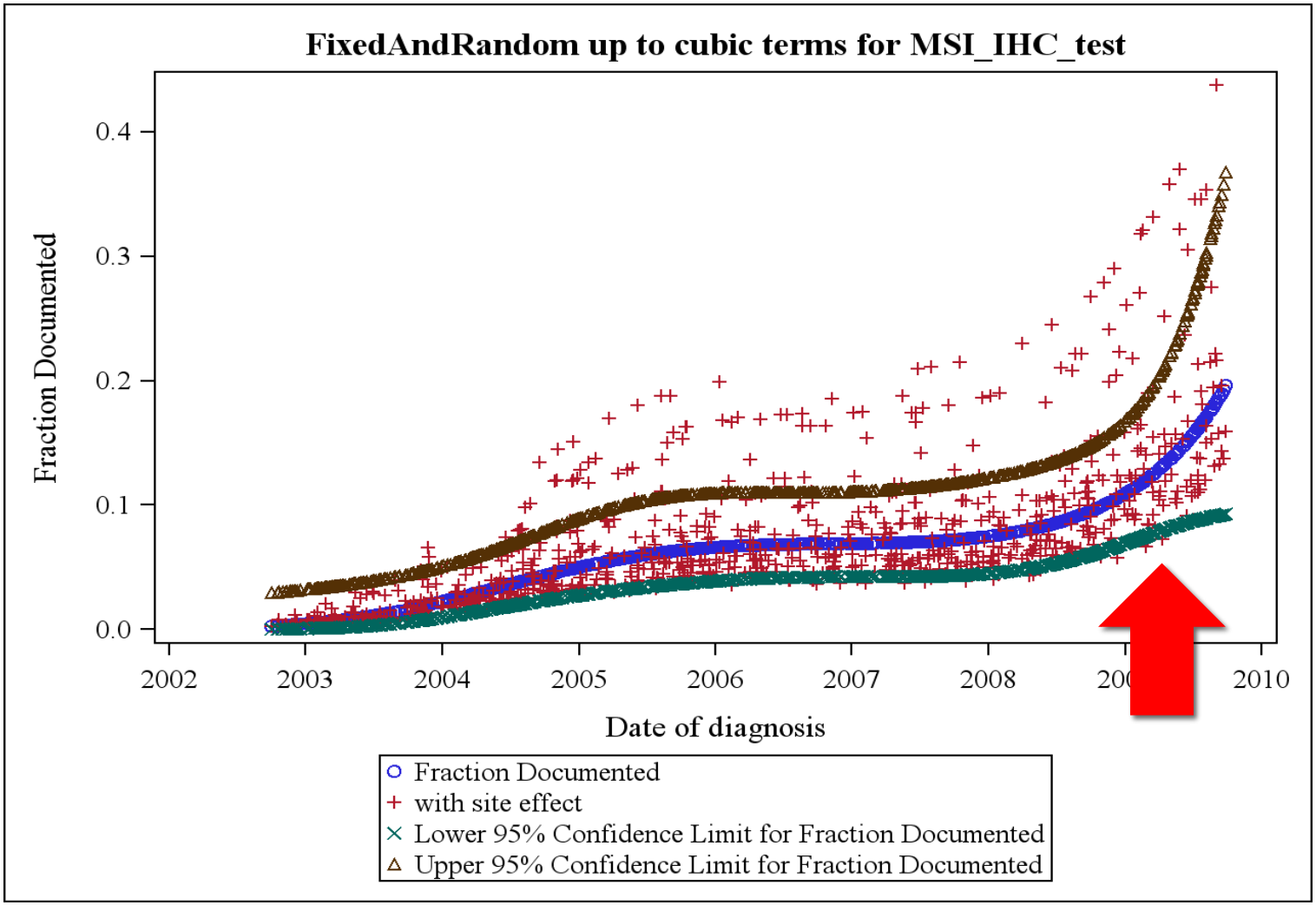
Key Informant Interviews

Barriers and facilitators of routine genomic services for CRC patients

Clinical and demographic characteristics

	N=886 (range or %)
Age	46 (19-55)
Male	812 (92)
Race	
White	518 (62)
African American	298 (35)
Tumor Stage	
0 to 1	196 (25)
2	196 (25)
3	227 (28)
4	181 (23)
Surgical resection	780 (88)
Chemotherapy	555 (63)

Trend in molecular analysis of tumor tissue from 2003 through 2010



Journal of *Personalized Medicine*

MDPI

Article

Barriers and Facilitators to Adoption of Genomic Services for Colorectal Care within the Veterans Health Administration

Nina R. Sperber [1,2,*], Sara M. Andrews [1], Corrine I. Voils [1,2], Gregory L. Green [3], Dawn Provenzale [4] and Sara Knight [5,6]

Molecular testing of tumor--advantageous and available, but seldom used

- Most clinicians see few cases of younger patients diagnosed with CRC
- No request and approval routines
- Low cost of testing is advantageous

Desire for expert support, but variable access

- No standard referral process for consultation
- Need expertise to talk with patients about genetics and genomics
- Little awareness of where to obtain expertise, such as genetic counseling
- But, clinical geneticists and genetic counselors perceived as valuable

Aligning policy and healthcare services for return of results with genome sequencing with the values and preferences of diverse Veterans

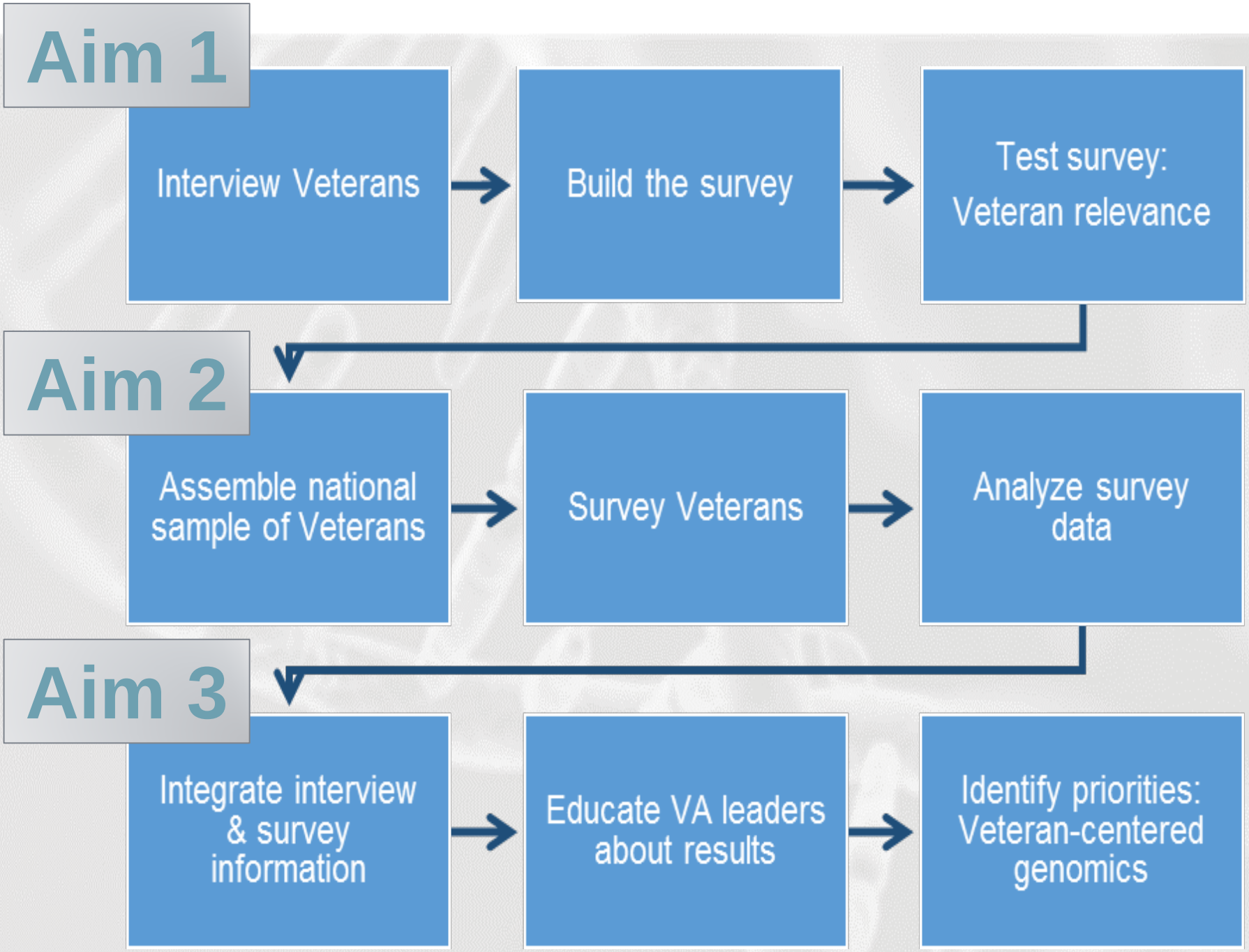
- What do Veterans from diverse groups want to learn about from genome sequencing? Secondary findings from diagnostic evaluation? Research results?
- Do Veterans want only medically actionable results? What else would they want to learn about from genome sequencing?
- What are the optimal healthcare services for the delivery of Veteran-centered return of results from Whole Genome Sequencing?

Limitations of patient engagement methods to improve health services design

- Community outreach creates interest, but potentially overlooks reluctance to participate
- Advisory committees can promote tokenism
- Typical focus groups may capture initial and intuitive responses to an issue, potentially superficial
- Responses to surveys not deeply informed
- Consensus panel methods force premature agreement

Addressing study design challenges

- Population-based sample of Veterans with sufficient sample size to examine differences in values and preferences of subgroups
- Early study that comprehensively engages patients and key healthcare system decision makers at a national level in setting priorities for return of results from WGS.
- Diverse Veterans will have a voice in and will contribute to shaping how genomic healthcare services are delivered in VA.


Aim 1
Interview Veterans
Build the survey
Test survey:
Veteran relevance
Aim 2
Assemble national sample of Veterans
Survey Veterans
Analyze survey data
Aim 3
Integrate interview & survey information
Educate VA leaders about results
Identify priorities: Veteran-centered genomics

Aligning genomic health services with values and preferences of diverse Veterans

- Need for a multi-way, iterative dialogue between people impacted by the policy, researcher, and policy maker
- Transparency and accountability to the Veterans
- Policies developed with public participation perceived as more legitimate, trusted, and likely to be implemented than those without engagement

Democratic deliberation

- Method for public input on policies
- Includes education and interaction with other citizens and experts
- Participants are able to provide feedback and input on policies that are informed by thorough reflection

Multi-level, multi-process stakeholder engagement

Informs ethical considerations, research methods, and translational activities

Patients, Family Members,
Clinicians,
Health System Executives,
Community Leaders

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