Communication and Decision Making for Individuals with Inherited Cancer Syndromes

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NIH NATIONAL CANCER INSTITUTE

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Basis for RFA

Blue Ribbon Panel Recommendation G

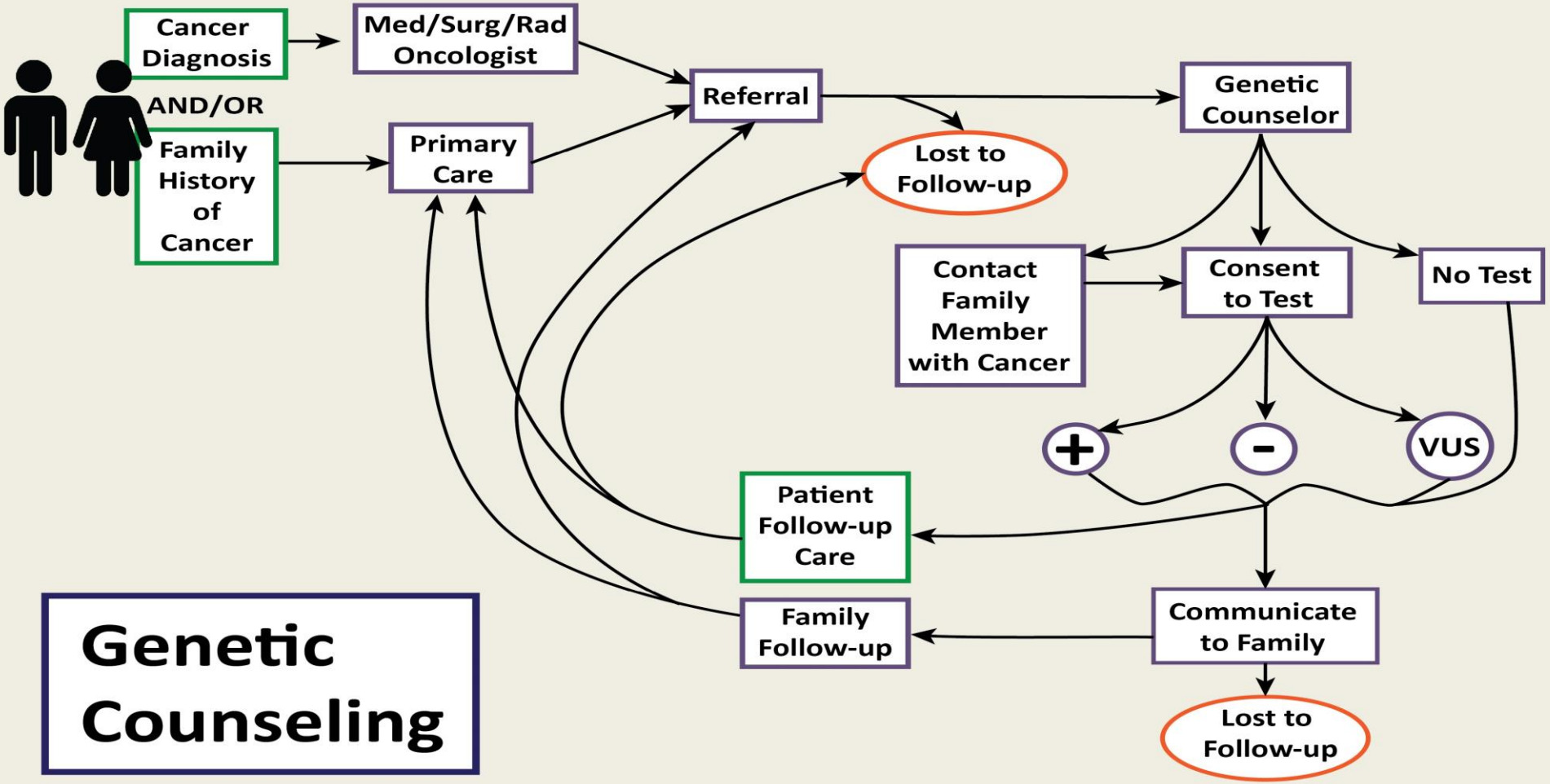
"…improve the current state of early detection, genetic testing, genetic counseling…"

February 2017 Workshop: The Case of Lynch Syndrome

- Meeting scope: Genetic testing approaches, current practices, healthcare delivery approaches, case ascertainment in hereditary cancers
- Major theme: Need for studies on communication and decision making

RFA Goal

Develop, test, and evaluate interventions and implementation approaches, or adapt existing approaches, to improve patient/provider/family risk communication and decision making for individuals and families with an inherited susceptibility to cancer.


Cancer Diagnosis
Med/Surg/Rad Oncologist
AND/OR
Family History of Cancer
Primary Care
Referral
Lost to Follow-up
Genetic Counselor
Contact Family Member with Cancer
Consent to Test
No Test
+
-
VUS
Patient Follow-up Care
Family Follow-up
Communicate to Family
Lost to Follow-up
Genetic Counseling

Background: Counseling, Communication, Decision Making

- Communication is essential to understanding risk and managing uncertainty

- Understanding risk is influenced by many factors (e.g., cognitive biases, cultural beliefs, personal illness experiences, family history of cancer)

- Communication strategies are needed to:
  - Promote guideline-concordant genetic testing and follow-up healthcare
  - Facilitate disclosure of genetic test results to family members
  - Improve the counseling process for the return of an uninformative test result (e.g., variant of uncertain significance)

Aims of the RFA

Solicit U01 applications that develop, test, evaluate, and implement interventions, or adapt and implement existing interventions that address:

- Patient-level communication approaches to genetic counseling and testing that promote understanding of genetic risk and help guide clinical management decision making
  - technological
  - oral (in person, phone)

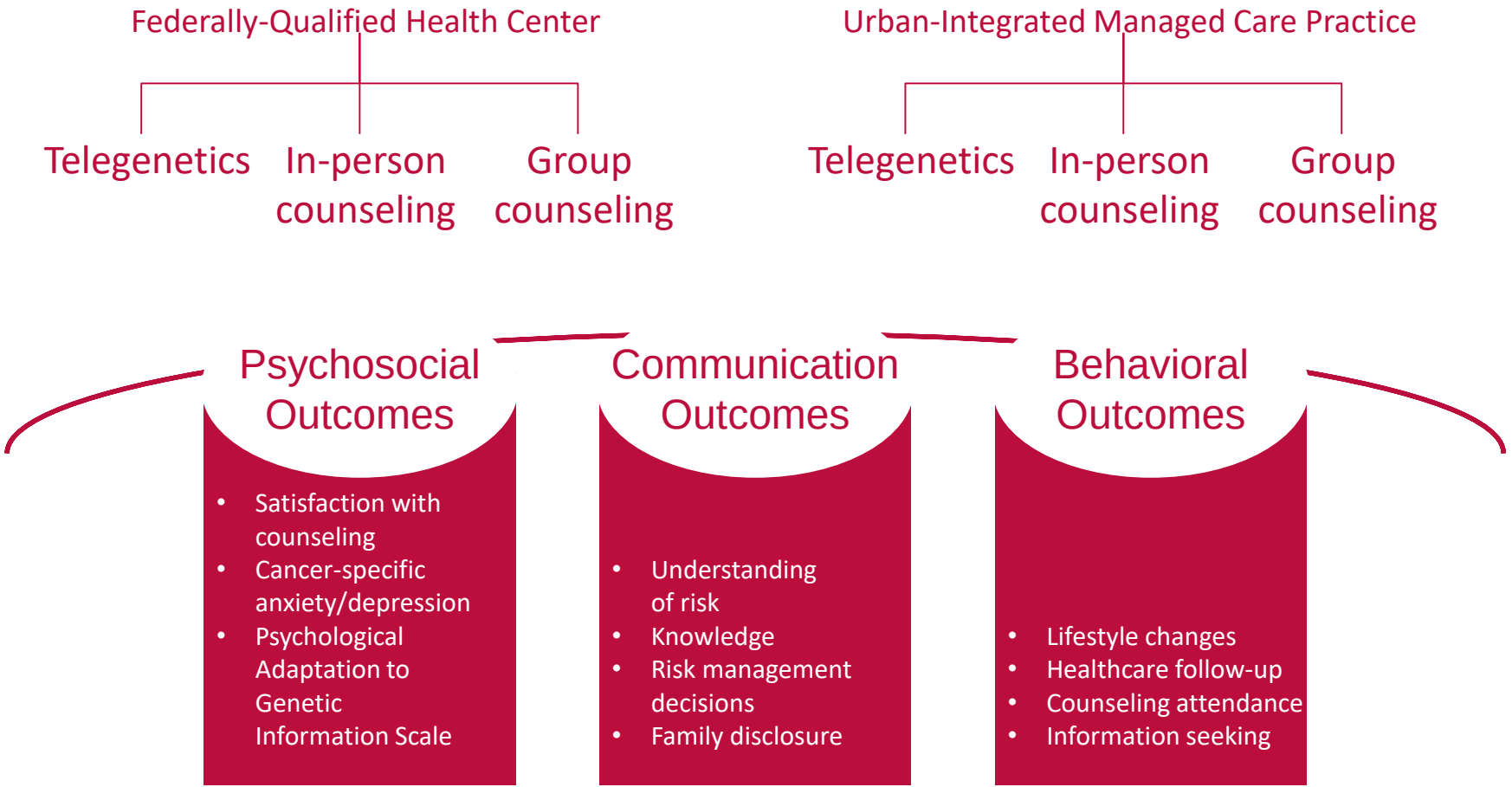
- Communication approaches for cancer risk disclosure to at-risk family members

- Tailored communication strategies that address the unique needs of underserved populations (e.g., low-income, minority, rural, low literate, low numerate, non-English speaking)

- Decision-making tools and techniques that promote understanding of risk and improve clinical management decision making

RFA: Communication and Decision Making for Individuals with Inherited Cancer Syndromes

- Studies of **ALL** inherited cancer syndromes are encouraged
- Studies of **ALL** at-risk individuals are encouraged
- Studies across a variety of genetic counseling methods and providers
- Studies that address racially/ethnically, socioeconomically, and geographically diverse populations
- Clinical trials – strongly recommended


Federally-Qualified Health Center
Telegenetics
In-person counseling
Group counseling
Urban-Integrated Managed Care Practice
Telegenetics
In-person counseling
Group counseling
Psychosocial Outcomes
Satisfaction with counseling
Cancer-specific anxiety/depression
Psychological Adaptation to Genetic Information Scale
Communication Outcomes
Understanding of risk
Knowledge
Risk management decisions
Family disclosure
Behavioral Outcomes
Lifestyle changes
Healthcare follow-up
Counseling attendance
Information seeking

Evaluation Criteria

- Facilitate understanding of genetic risk and delivery of genetic counseling, and improve clinical management decisions
- Include racially/ethnically, socioeconomically, and geographically diverse populations, including medically underserved groups (e.g., minority, rural, low-income, low literate, non-English speaking)
- Address disparities in communication related to genetic counseling and testing, and risk management decision making
- Focus on a variety of clinical settings and counseling methods
- Demonstrate interdisciplinary collaborations
- Demonstrate evidence of research productivity and impact of publications

Portfolio Analysis

An NIH-wide portfolio analysis was conducted for funded extramural research projects specifically focused on approaches to optimize communication and decision making in the context of inherited cancer syndromes (2015-2017)

- 10 grants related to genetic counseling, communication of genetic information, or decision making

- **No grants broadly focus on hereditary syndromes.**
  - 9/10 focus exclusively on hereditary breast and ovarian cancer
  - 2/10 address multi-gene panel testing
  - 2/10 address challenges of communicating with diverse populations
  - 1/10 addresses communication of VUS results

Budget

- Mechanism U01
- Number of Awards 5
- Fiscal Years 2019-2023
- Annual Cost $5M/year
- Total Costs $25M

Summary of Proposed RFA

- Addresses Recommendation G of the Blue Ribbon Panel Report
- Complements RFA-CA-17-041 by addressing communication and decision making that need to be part of the health care delivery process for individuals with inherited cancer syndromes
- Seeks to establish best practices for how to communicate genetic risk in the context of uncertainty
- Encourages projects that develop, test, evaluate, and implement effective risk communication strategies for diverse populations and clinical settings
- Encourages projects that develop or improve approaches to communicating health information via technology
- Encourages studies of all inherited cancer syndromes

Response to Subcommittee Concerns/Questions

How do we measure the success of the proposed interventions?
Examples of outcomes: Adherence to guideline-concordant testing/follow-up, outreach to diverse populations, outreach to at-risk relatives and referrals, cascade testing for relatives

How can you tailor communication strategies for underserved populations if genetic counseling is not offered?
Technology (e.g., telegenetics, web-based counseling) can be used to reach underserved groups, such as rural, minority, non-English speaking populations; also requires strategies to reach underserved populations.

How does risk communication in the context of inherited cancer differ from other situations?
Communication can be complex and fraught with uncertainty regarding receiving counseling, testing, and choice of a management strategy; testing results may have significant implications for the individual, family members, and future offspring; uninformative test results can engender extreme emotional outcomes.

Must projects focus on at least two clinical settings?
No, but studying multiple settings is encouraged.

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National Institutes of Health / National Cancer Institute

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