University of California
San Francisco

# Communicating Effectively about Cancer Genetics with Patients of Low Health Literacy

## National Cancer Policy Forum Workshop

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# What do we mean by cancer genetics?

Personalized Medicine

Precision Medicine

Genomics

Computational Medicine

Prevention: Risk assessment using polygenic risk scores or PRS

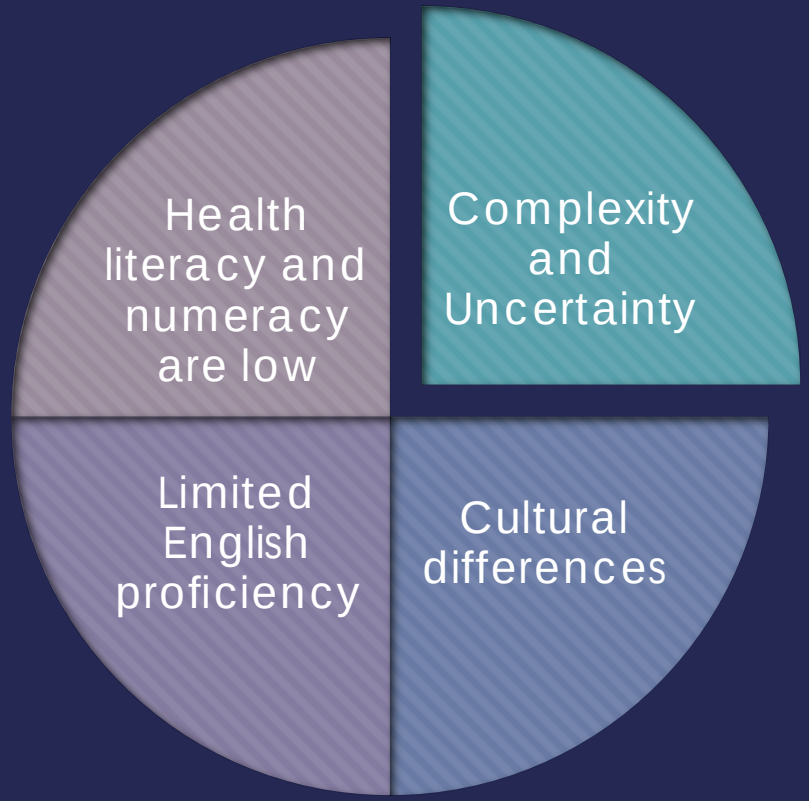
Prevention/Treatment: Germline testing and genetic counseling for hereditary cancer

Treatment: Molecular tumor testing and targeted treatments

# Challenges Integrating Genetics into Cancer Care

- *Underrepresentation in genomic databases increases potential for inequities*
  - *E.g. lack of diversity in Genome Wide Association Studies (GWAS) → less accurate/potentially harmful use of polygenic risk scores; more uncertain results in hereditary cancer testing*
- Diversity Imperative for Genomics Research
  - *All of Us Research Program*
  - Other NIH initiatives e.g. *Clinical Sequencing Evidence-Generating Research Consortium (CSER2)*
- *Genomic Literacy is low*

# Genomic literacy is necessary to realize the promise of Genomic Medicine



# Relevance for the general population

"Communication is the most common procedure in medicine"

- Physicians commonly overestimate patients' literacy (and numeracy) levels
- Health information and the healthcare system can be difficult even for highly skilled people to navigate
- A new diagnosis or a stressful medical situation can make it hard anyone to understand

# Communication in Genetic Counseling for Hereditary Breast & Ovarian Cancer (HBOC)

- *Translating Cancer Genetics to the Safety Net Setting* (2012-2017)

- Research Questions:
  - How do these communication challenges play out in cancer genetic counseling in safety net settings?
  - What can we do to improve the communication?

# Results: Information Mismatch

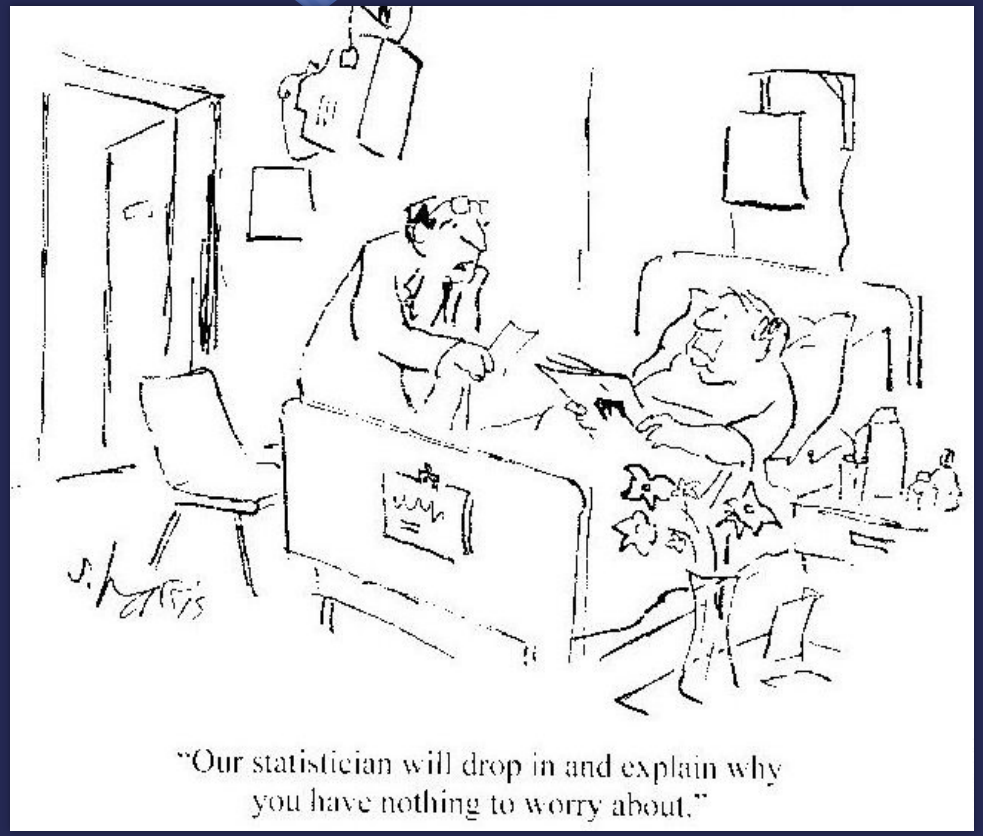
1. Too Much Information
2. Complex Terminology and Conceptually Difficult Presentation of Information
3. Information Perceived as not Relevant by the Patient
4. Counselors Unintentionally Inhibited Patient Engagement and Question-Asking
5. Vague Discussions of Screening and Prevention Recommendations

Joseph, G., et al (2017). Information Mismatch: Cancer Risk Counseling with Diverse Underserved Patients *Journal of Genetic Counseling*, *26*(5), 1105-1105.

# Principles of Effective Communication

- The clinician, not the patient, is responsible for effective communication.
- The ‘universal precaution principle’: *all patients may benefit* from plain language
- Patient comprehension can and should be verified
- Adapting for literacy/numeracy level requires commitment, flexibility, and practice.

# Intervention Development/Pilot




- Training on Effective Communication for Genetic Counselors
  - ✓ Recognize Limited Literacy
  - ✓ Use Plain Language
  - ✓ Focus on Key Messages & Avoid TMI
  - ✓ Use Risk Communication Best Practices (e.g. frequencies & absolute risks)
  - ✓ Assess Comprehension
  - ✓ Working with LEP patients & Interpreters

**Joseph G,** et al. Effective communication in the era of precision medicine: A pilot intervention with low health literacy patients to improve genetic counseling communication. Eur J Med Genet. 2018 Dec 12. pii: S1769-7212(18)30457-9

# CHARM:
# Cancer Health Assessment Reaching Many

cser
Clinical Sequencing Evidence-Generating Research

- Purpose: to increase access to genetic testing for hereditary cancer in “underserved populations”
  - Low income
  - Low literacy
  - Minority populations
- Patients aged 18-49 years
  - Kaiser Permanente Northwest
  - Denver Health a federally-qualified healthcare center
  - English or Spanish Speakers

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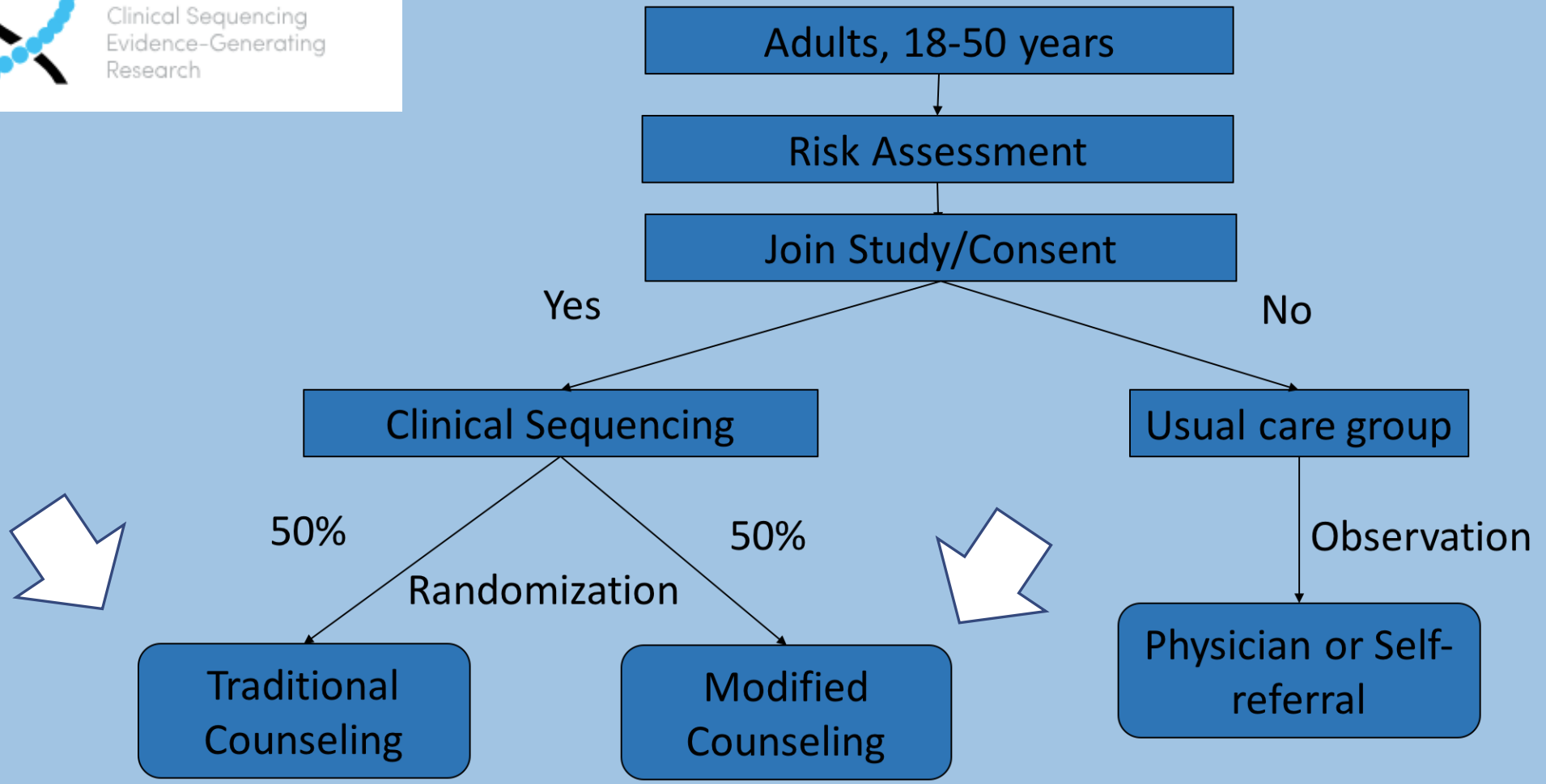
Clinical Sequencing Evidence-Generating Research

CHARM
Cancer Health Assessments Reaching Many

NHGRI/U01 MPI: Goddard/Wilfond




Surveys @ Baseline, 2 weeks, and 6 months

Compare utilization between study ppts and usual care

# Approach to Communication in CHARM

- ✓ All materials designed for accessibility for limited health & genomic literacy *with stakeholder input*
- ✓ All translated *& culturally adapted* to Spanish
- ✓ Web-based consent with illustrations and audio
- ✓ Training of medical interpreters on exome sequencing

# Results Disclosure

Saliva sample for clinical exome sequencing

Categories of Results:

- Cancer Risk: 39 genes
- Medically Actionable: 79 genes
- Carrier: 14 genes

Genetic counselors return results by phone

# Traditional: Usual Care

- **Conceptually and linguistically complex**
  - Analogies/hypotheticals
  - Jargon/technical language
  - Passive voice to convey uncertainty indirectly
- **Emphasis on Education**
  - Detailed genetic information
  - Unidirectional transfer of information from counselor to participant

Joseph, G., et al (2017). Information Mismatch: Cancer Risk Counseling with Diverse Underserved Patients *Journal of Genetic Counseling*, *26*(5), 1105-1105.

# Modified: Literacy Focus

**Conceptually and linguistically simplified**

- Direct & concrete
- Plain language
- Active voice to minimize uncertainty

**Emphasis on Communication and Psychosocial Counseling**

- More dialogue & participant engagement
- Focus on relationship building, rapport, empathy

# Modified Counselor Training Overview

Session 1: Recognizing Limited Literacy
Session 2: Adapting your approach
Session 3: Assessing Comprehension
Session 4: Risk Communication
Session 5: Working with LEP patients and Interpreters
Session 6: Review/Practice/Discuss

- ✓ Observations of other counselors
- ✓ Ongoing case conferences to discuss cases, review methods, share ideas

# Data and Outcome measures

## Baseline, 2 week, 6 month surveys (n= ~880)

- Demographics
- Communication
- quantity of information
- understanding of cancer risk and recommended f-u care
- satisfaction
- quality of interpretation

## Qualitative Interviews

- 2-3 weeks after RD (n=50)
- re-interviewed at 6 months (n=25)
- How and why the modified counseling works/doesn't work
- Family communication
- Follow up care

## Audio Recordings of Results Disclosure calls

- Coding for fidelity to Modified/Traditional
- Used to tailor Qualitative Interviews

# Next Steps/Topics for Discussion

- Beyond supplemental training--integrate into graduate education
  - Emphasize relationship building vs information/education
- Changes in genetic counseling—quickly evolving field
  - Focus on test results vs pre-test counseling
  - Shortage of GCs
  - Larger and larger genomic tests
- Not just about genetic counselors--
  - Explosion of Direct-to Consumer testing
  - Managing risk and screening in primary care

# CHARM study team

CHARM
Cancer Health Assessments Reaching Many

### Kaiser Permanente Northwest
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# Thank you!

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