

# Asian American Patient Experiences in Genetic Counseling and Testing

A Systematic Review of the Literature

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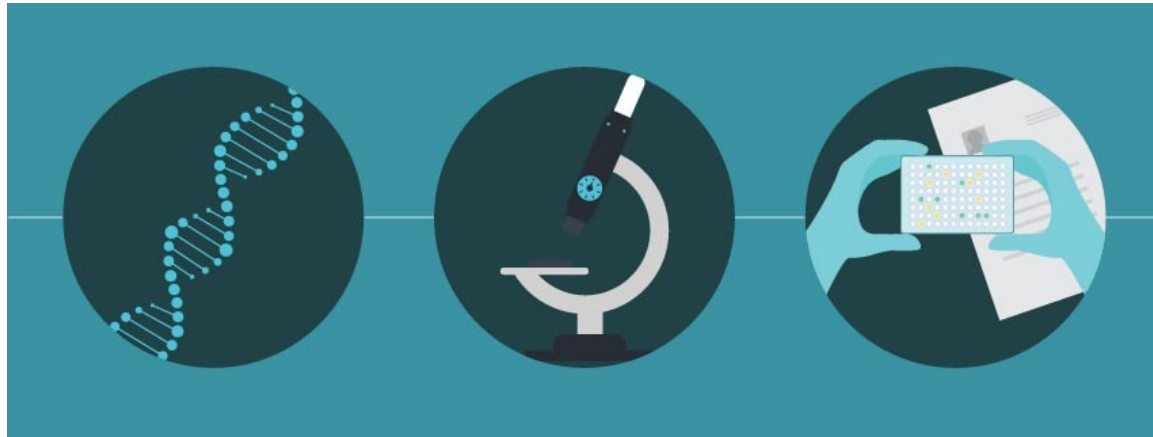
*Asian American Research Center on Health Meeting*  
*11.19.2020*

# Precision Medicine & Clinical Genetics

Genetic counseling and testing is increasingly integrated into clinical care

Potential to transform our ability to tailor diagnostics, prevention, and treatment

Just like any other health service, precision medicine technologies such as genetic counseling and testing has the potential to exacerbate health disparities



# Asian Americans Face Biases in Health Care

- Racial stereotyping and labeling
- “Model Minority Myth” applies to healthcare settings
  - Asian Americans do not experience health disparities to the same extent
- Providers are less likely to follow evidence-based guidelines and meet standards of care with Asian American patients



# Current Study

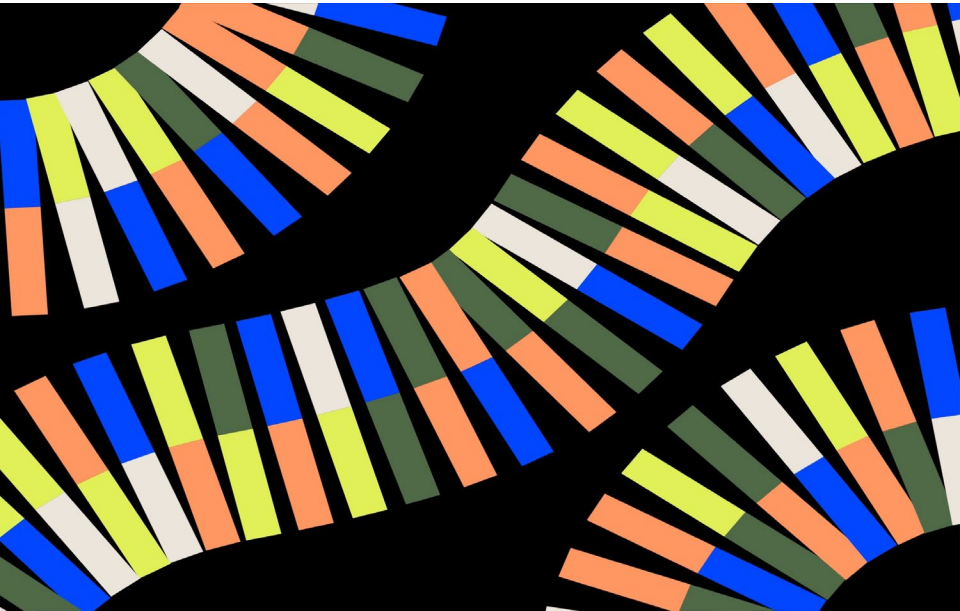
**Rationale**: Unique needs of Asian American patients have not been well studied in genetic counseling and genetic testing

**Goal**: Identify, evaluate, and summarize the findings of all relevant qualitative and quantitative research on genetic services for Asian Americans

**Secondary goal**:  
Investigate how researchers defined this population

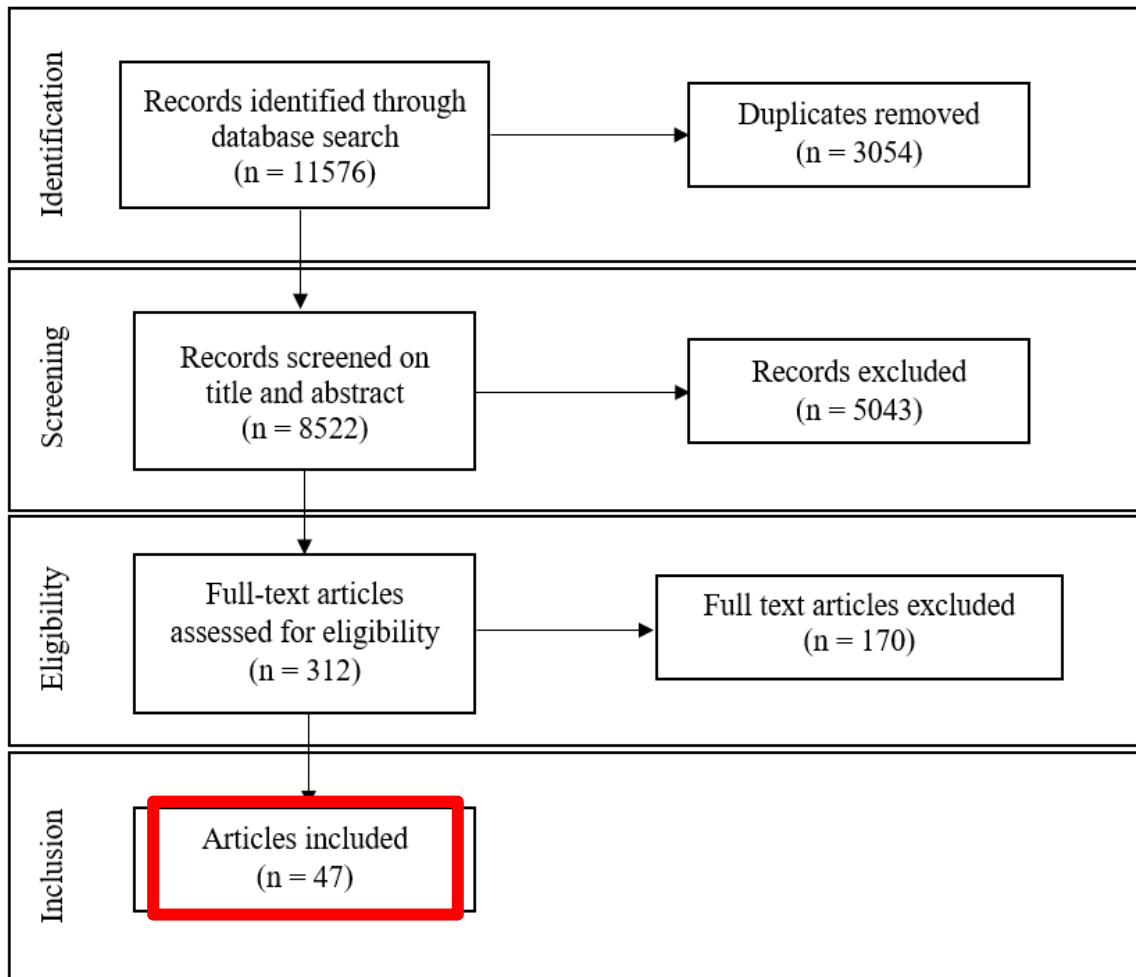


# Methods



- Peer reviewed, empirical studies published 1990-2018
- Five databases: PubMed, Embase, PsychInfo, CINAHL, and Social Science Abstracts
- “Asian American” AND “Genetic Testing” OR “Genetic Counseling”
- 20 largest Asian origin subgroups included in search
- Joanna Briggs Institute (JBI) convergent approach for mixed methods systematic literature review

## Preferred Reporting Items for Systematic Reviews (PRISMA) flow diagram

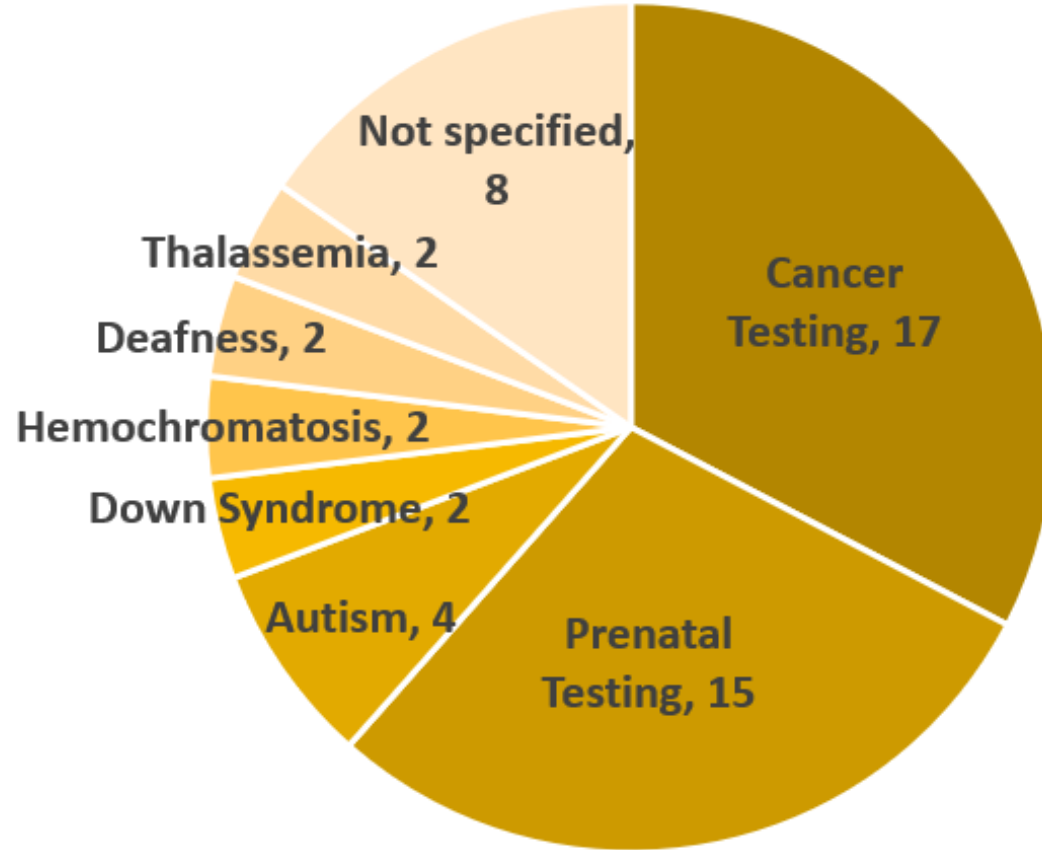


# Results

Study Characteristics	n	% (out of 47)
Qualitative studies	15	32%
Quantitative studies	32	68%
Female majority sample	38	81%
Female only sample	20	43%
Genetic counseling	11	23%
Genetic testing	10	21%
Genetic counseling & testing	2	4%
Hypothetical scenarios	16	34%
Conducted on West coast (CA, OR, WA)	20	43%

# Results

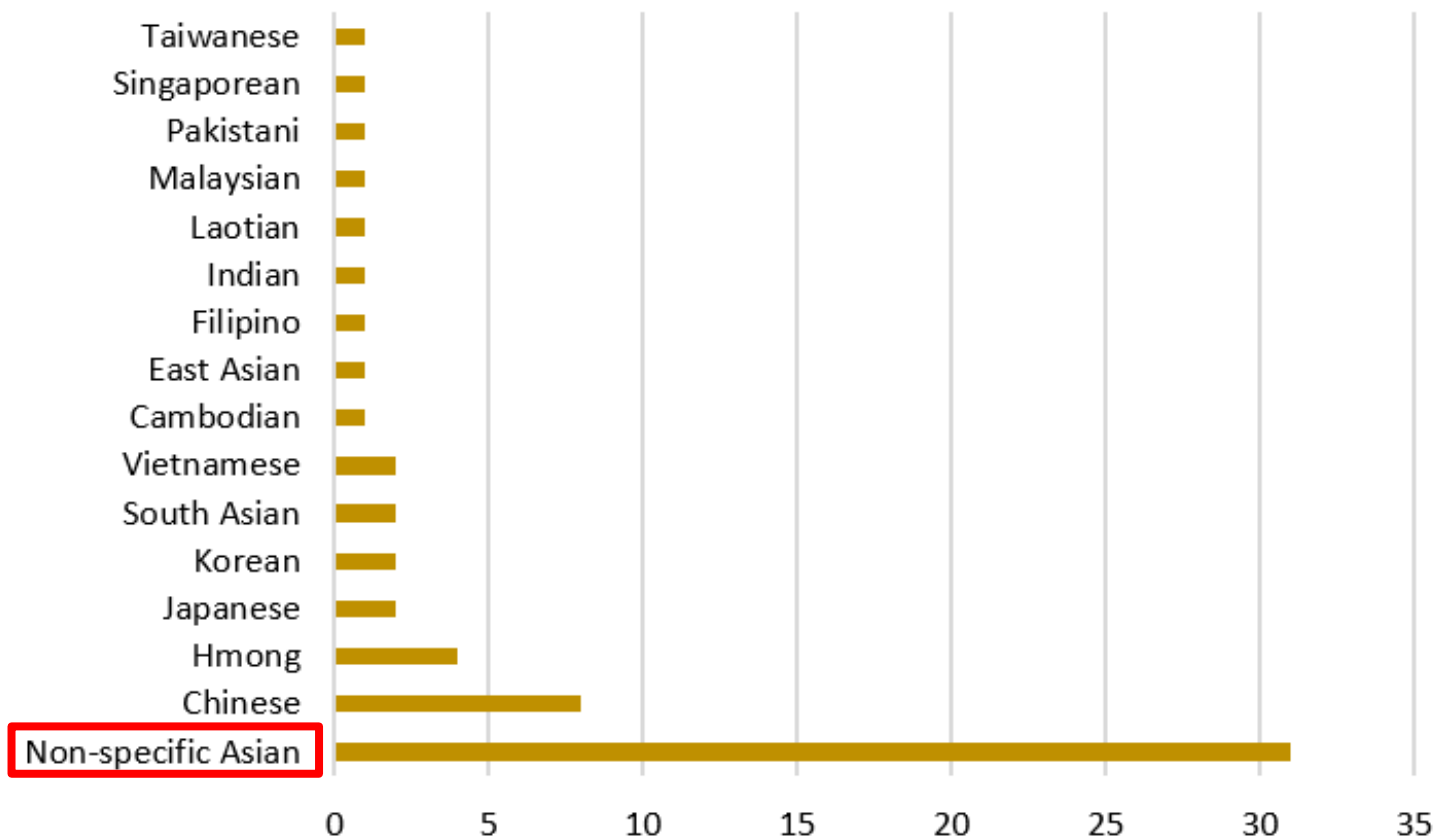
## Conditions Studied





# Results

## Asian American Sample



# Results: Themes from the Literature

## 1. Access and awareness

- Barriers to accessing services
- Lowest levels awareness of services among racial groups (related to nativity/residence length)

## 2. Attitudes

- Overall positive, in favor of genetic testing
- More concerned by psychosocial impacts, less concerned with insurance coverage
- Also more in favor of non-health genetic testing (IQ, sex selection) than EA

## 3. Genetic testing uptake

- High rates, similar to other racial groups
- Actionability was a consideration

# Results: Themes from the Literature

## 4. Communication barriers

- Complex content contributed to misunderstanding of crucial information

## 5. Family factors

- Family members were heavily involved in genetic testing decisions
- Selective family communication

## 6. Cultural factors

- Disease stigma contributed to negative views of genetic testing
- Marriage prospects in the future

# Discussion: Key Barriers

- Low referral rates
- Language gaps
- Interpretation quality
- Communication styles
- Family cascade testing



# Discussion: Gaps in the Literature

## Gaps

- Lack of specification of Asian subgroup
- No subgroups comparison heterogeneity uncaptured
- Lack of analysis with other demographic variables
- Lack of diversity – gender of participants and conditions studied

## Recommendations

- Disaggregation of Asian American data and more detailed measures of race/ethnicity
- Collection and comparison of subgroup data
- Inclusion of broader demographic factors and multivariate analyses
- Broader range of health conditions included, oversampling of underrepresented genders

# Implications: Health Equity in Genetic Medicine

Increase funding to support Asian American genetic health research

Build trust, and engage historically marginalized groups in research

Integrate evidenced-based health services approaches developed in other healthcare fields





## NHGRI Strategic Vision: Bold Prediction

*“individuals from ancestrally diverse backgrounds will benefit equitably from advances in human genomics”*

In order for this prediction to come to fruition, we must address the research gaps and healthcare barriers identified in this review

# THANK YOU!

**Feedback or Questions? Please contact:**

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# References

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