



**C**ogent **S**yndicated  
**G**enomics  
**A**ttitudes &  
**T**rends: **2005**



## BACKGROUND



# OBJECTIVES

## OVERARCHING GOAL

To provide a comprehensive and actionable assessment of Americans' views towards genomics in order to inform industry strategy and policy development.

## KEY AREAS OF EXPLORATION

- Awareness, favorability, and interest
- Catalysts and barriers
- Preferences for delivery
- Messaging and communications

# RESEARCH DESIGN

## METHODOLOGY

Population:	US Adults (18+)
Methodology:	Web survey
Sample Profile:	Representative of US population on age, socio-economic profile, ethnicity, region, and gender
Data Collection Period:	January 14 <sup>th</sup> – 31 <sup>st</sup> , 2005
Survey Length:	205 questions
Sample Size (error):	n=1,018 ( $\pm$ 3.07 pp)
Wave:	Year 2 data

## ANALYSES

Demographic Analysis:	Primary demographics, Household, Health, Values
Psychographic Segmentation:	Beliefs, Hopes, Fears, Concerns



# SELECTED FINDINGS



# AWARENESS OF GENOMICS

## Awareness is broad...

## ...but not deep.

Only **4%** of Americans have heard "a lot"

**31%** of those who have heard/read something can't recall any details

Of the 69% who can recall details, more than half point to the **basic relationship between genes and health** and not the use of genes to optimize individual health.

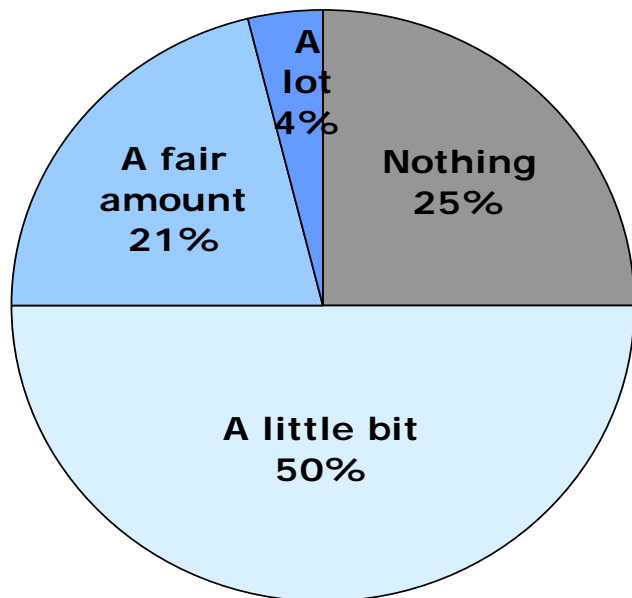
A few, however, seem to get it...

- Genes can be manipulated for health benefit (6%)
- Genes can lead to early diagnosis/detection (5%)
- Genomics can help customize treatments (3%)
- Genomics can help find cures for diseases (3%)
- Genomics can be used in prenatal stage (3%)

Awareness drops to **43%** when looking specifically at using genetic information to make informed choices about **prescription drugs**

**75%**

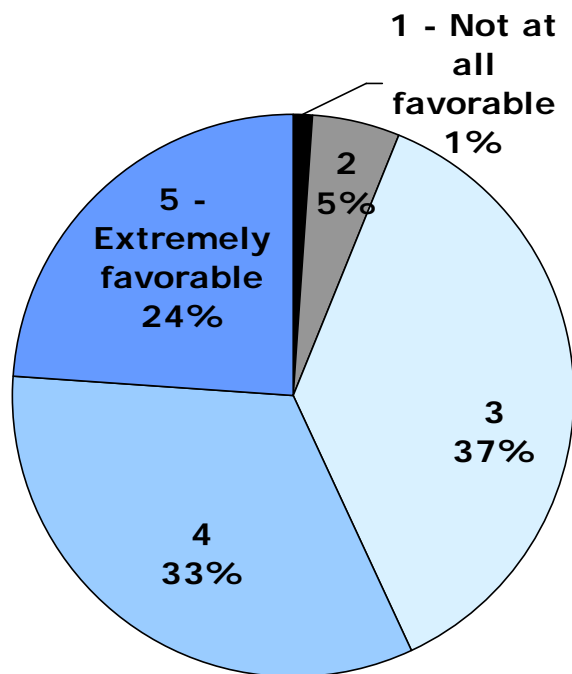
of Americans have heard or read something



Q22. Recent advances in science are making it possible to look at an individual's genetic profile (i.e. DNA) to determine a wide range of things about that person's current or future health. How much, if at all, have you heard or read about using individual genetic information to understand and optimize health?

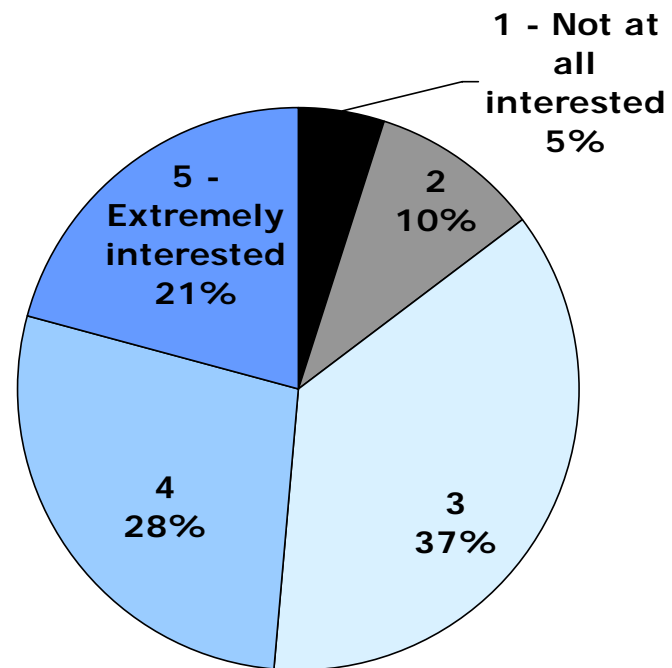
# ATTITUDES TOWARD GENOMICS

Americans are generally favorable toward the idea...



Q26. In general, how favorable are you toward the idea of using individual genetic information to understand and optimize health?

...and they are interested on a personal level



Q29. In general, how interested would you be in using your genetic information for the purpose of understanding and optimizing health?

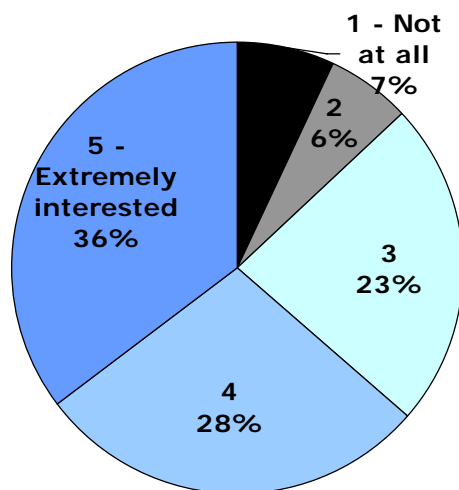
# ATTITUDES TOWARD PERSONALIZED MEDICINE

**58%** are **favorable** toward using individual information to make informed choices about prescription drugs

**51%** are **interested** in using their genetic information to make more informed choices about which prescription drugs to take

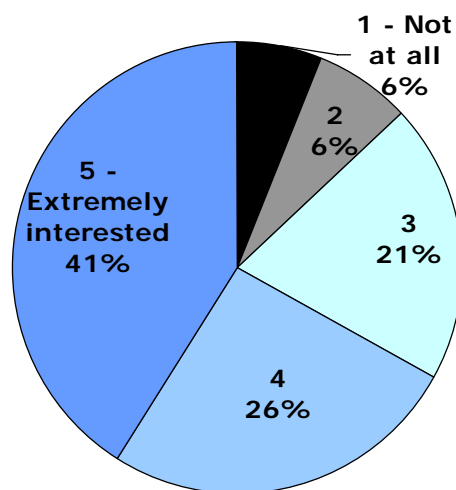
## Interest is high for...

Which drugs would be most effective in your body...



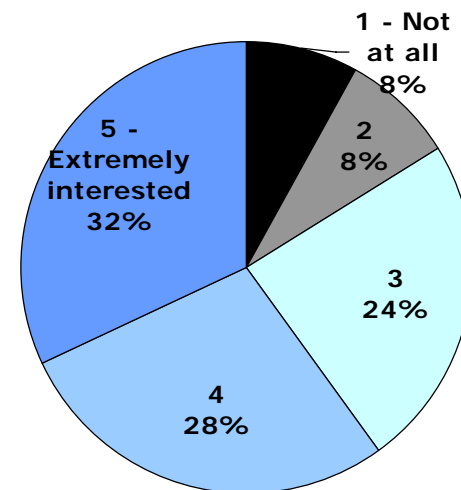
**64% INTEREST**

If you will have an adverse reaction to a drug...



**67% INTEREST**

Whether to take a drug preventively...



**60% INTEREST**



# INTEREST IS SOLUTION DRIVEN

**REDUCING MY RISK OF  
SPECIFIC DISEASES**  
(71% INTERESTED)

**VS.**

- Creating a record (50%)
- Improving appearance (39%)

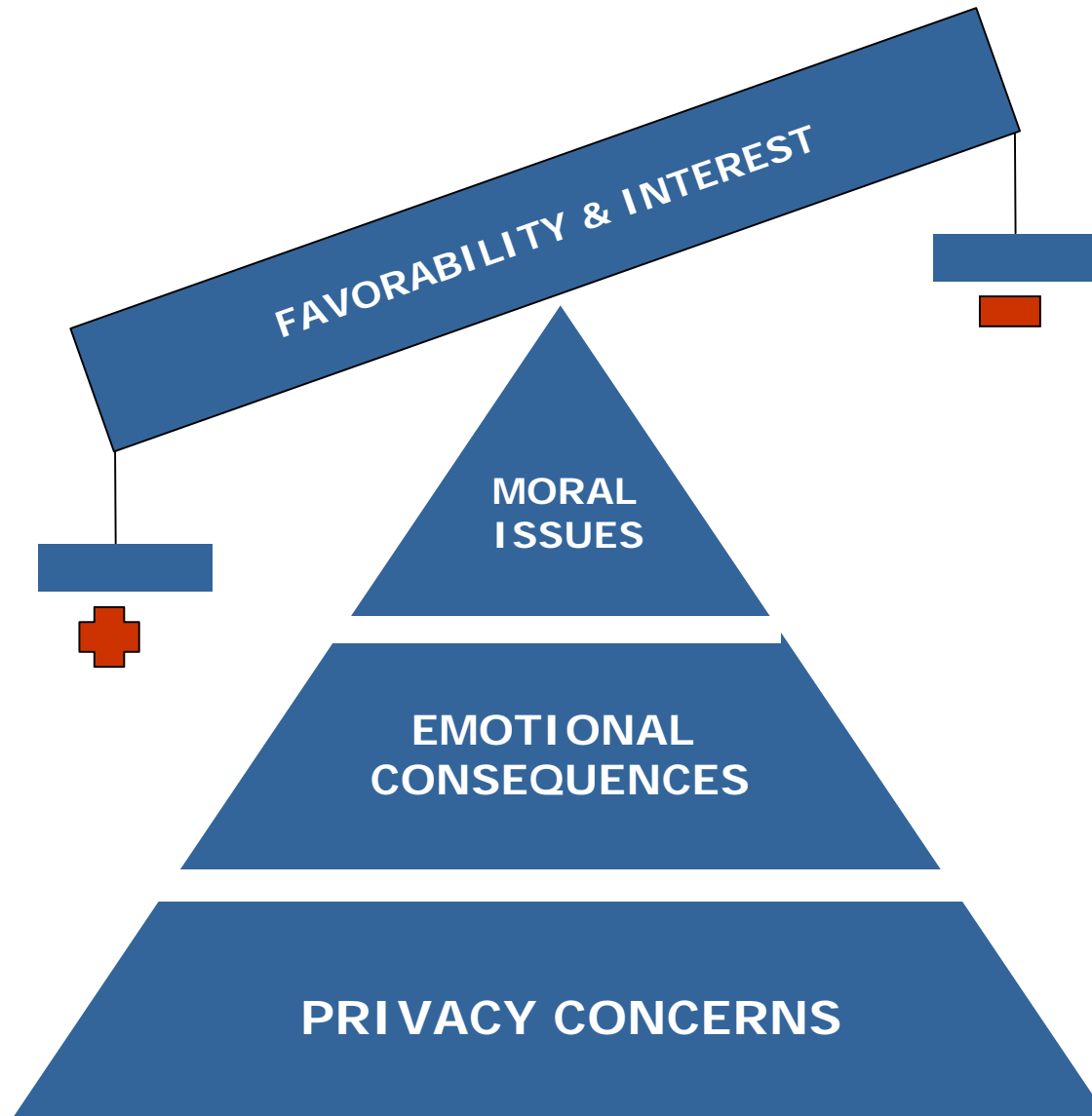
**IDENTIFYING  
DISEASES CERTAIN  
TO EXPERIENCE**  
(49% MORE INTERESTED)

**VS.**

- Carrying gene, but not whether developing condition (27%)

**CONDITION CAN BE  
TREATED**  
(26% INTEREST  
IF NOT  
TREATABLE)

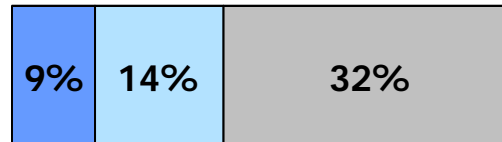
# FOUNDATION FOR ACCEPTANCE



# MORAL ISSUES

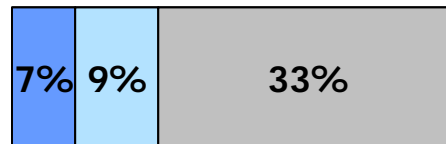
## A small group...*today*

Some of the recent advances surrounding the use of genetic testing make me uncomfortable from a moral standpoint.



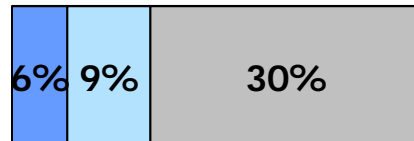
23% agree; 55% with fence sitters

Meddling with our genes and DNA is trying to play God. Scientists, researchers and doctors should stay out of it altogether.

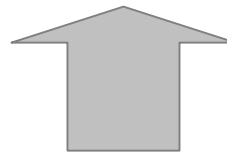


16% agree; 49% with fence sitters

Genetic testing should be stopped because it will ultimately lead to cloning or altering human genes.



15% agree ; 45% with fence sitters



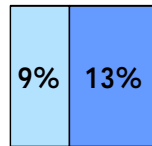
**FENCE SITTERS**

# EMOTIONAL COSTS

---

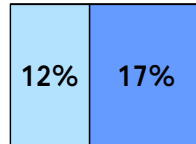
## It's a heavy burden to carry for some

Knowing my genetic profile is too great a responsibility because it impacts myself, my spouse, and ultimately, my children's lives.



**22%**  
agree

It would be too depressing to know I was going to get a disease, particularly if there is nothing I can do about it



**29%**  
agree

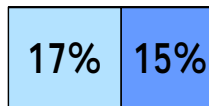
# PRIVACY MATTERS

**68%** are **concerned** about how personal genetic information would be stored and who would have access to that information

**31%** say their concern would **prevent them from having a genetic test** (out of *all* Americans)

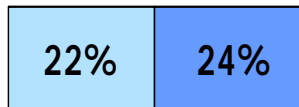
## Why?

I consider the results provided by DNA testing to be no more sensitive than the results provided by other tests



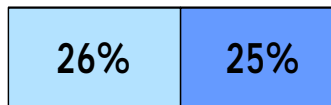
**32%**  
disagree

I'm torn on the use of genetics. The potential benefits are incredible, but the potential for misuse is considerable.



**46%**  
agree

I would worry that my DNA sample may be used for tests other than the ones I have authorized



**51%**  
agree

# FEAR OF MISUSE

## Americans do not trust insurance companies ...

## ...but want them to pay for their tests

Insurance companies will do everything possible to use genetic information to deny health coverage.



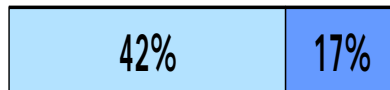
68% agree

Insurance companies will use information to deny coverage for drugs people need if genetic profile indicates low change of responding.



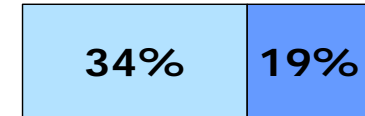
69% agree

The info would become part of your medical record and obtainable by insurance companies.



59% decrease in interest

Your health insurance would not cover the costs of genetic testing



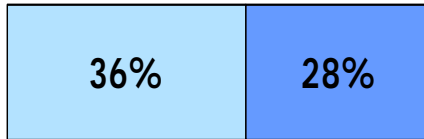
53% decrease in interest

# THE ROLE OF THE GOVERNMENT IN PRIVACY

## Americans want the government to protect their privacy...

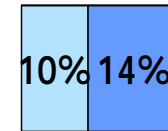
## ...but not have access to their information

You were assured that, by law, no one could access your DNA information without your consent.



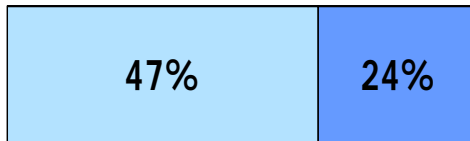
**64%**  
increase in  
interest

Gov't should create national database of DNA information for future health of all Americans.



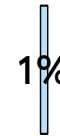
**24%** agree

Gov't should establish specific laws and regs to protect privacy of genetic information.



**71%**  
agree

Who, besides you, should receive a copy of the results of your genetic test? [check all that apply]



**1%** selected  
gov't health  
agency

# KEY LEARNINGS

---

- ▶ Deepen Americans' understanding of genomics
- ▶ Focus first on *diseases* where *solutions* exist
- ▶ Advocate for privacy protections - with limited involvement
- ▶ Address moral concerns *before* they become an issue



*To purchase the full report or  
for any inquiries, contact:*

**cwhite@cogentresearch.com**

*The selected report findings can be shared with outside parties only after receiving permission from Cogent Research. When such permission is granted, Cogent Research must be credited as the information source.*

Cogent Research, LLC  
125 CambridgePark Drive  
Cambridge, MA 02140  
617-441-9944  
[www.cogentresearch.com](http://www.cogentresearch.com)

