

Consumer Genomics Testing: Regulatory and Health Policy Issues

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Session Objectives



Address data sharing, privacy, and security issues in the context of consumer genomics testing



Explore the landscape of emerging regulatory issues in consumer genomics



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How is Sally's Data Protected?

TERMS OF SERVICE



FEDERAL TRADE COMMISSION

Free publications for America's consumers

	Research Consent		Research Consent & Individual Data Sharing Consent	
	23andMe	Research Collaborators	23andMe	Research Collaborators
Aggregate Level Information	✓	✓	✓	✓
De-identified Individual Level Information	✓		✓	✓



With whom might Sally's data be shared?

Prevent unauthorized access in Research and Clinical Care

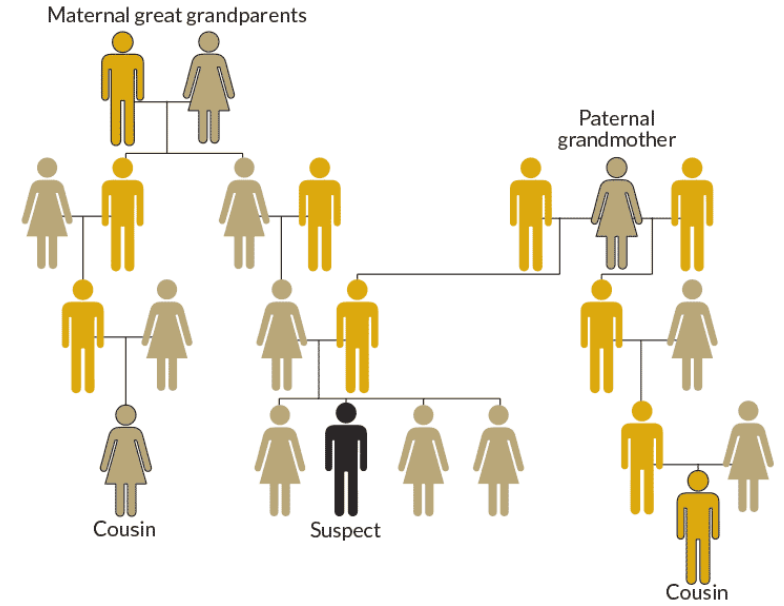


Protect against
discriminatory
use





Law Enforcement Access to Consumer Genomic Information



Whose privacy are we worried about?

Chr	Start Location	End Location	Centimorgans (cM)	SNPs
3	36,495	5,800,005	17.6	2,345
3	67,728,488	199,310,226	132.1	26,449

Match #1

Chr 3



Chr	Start Location	End Location	Centimorgans (cM)	SNPs
3	36,495	5,168,135	15.8	2,114
3	104,270,146	168,695,458	57.2	13,878

Match #2

Chr 3

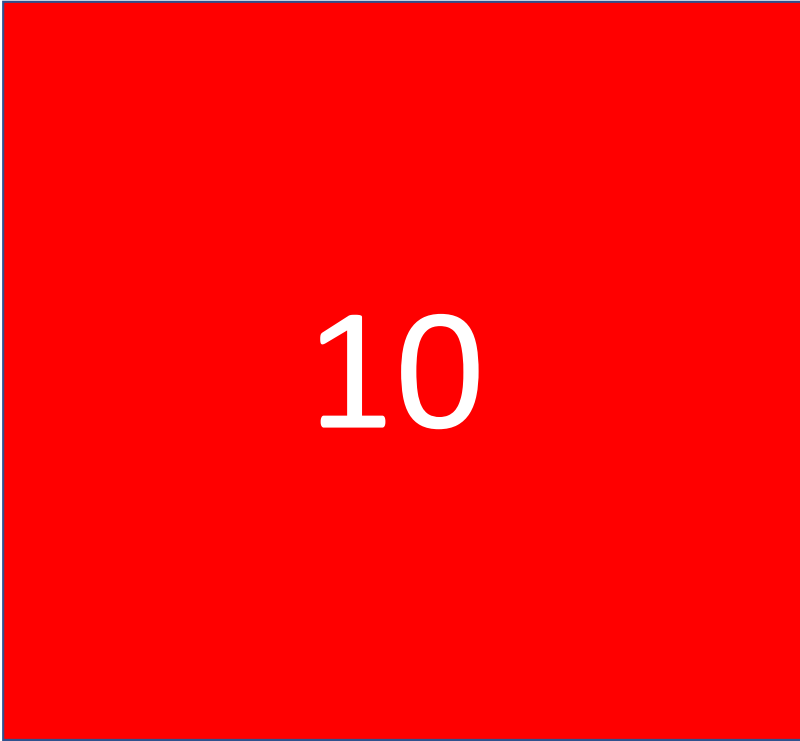


Chr	Start Location	End Location	Centimorgans (cM)	SNPs
3	104,090,483	114,098,727	7.4	2,130

Match #3

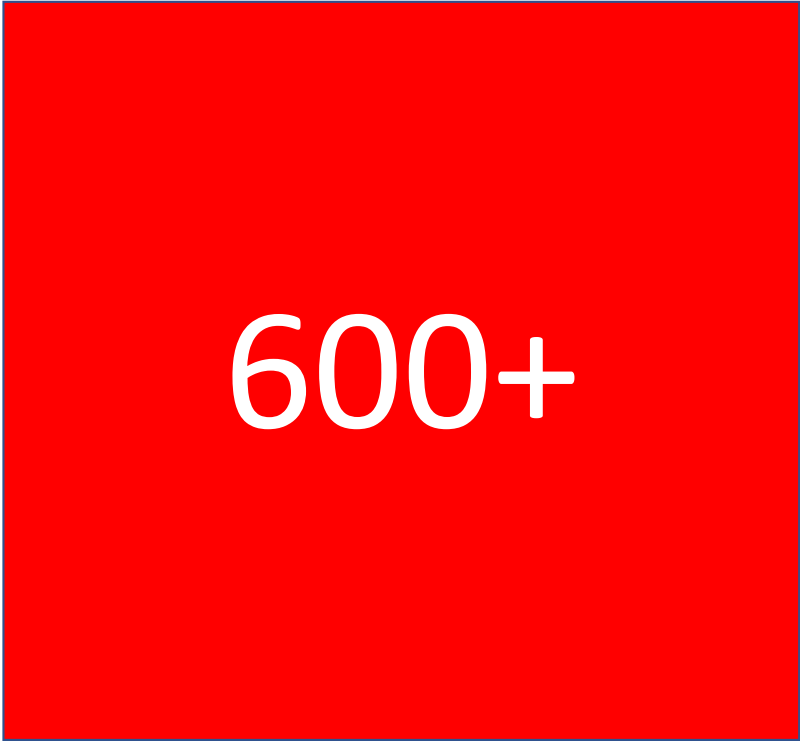
Chr 3





10

Max Persons of Interest
tested in 4 cases as a
result of IGG



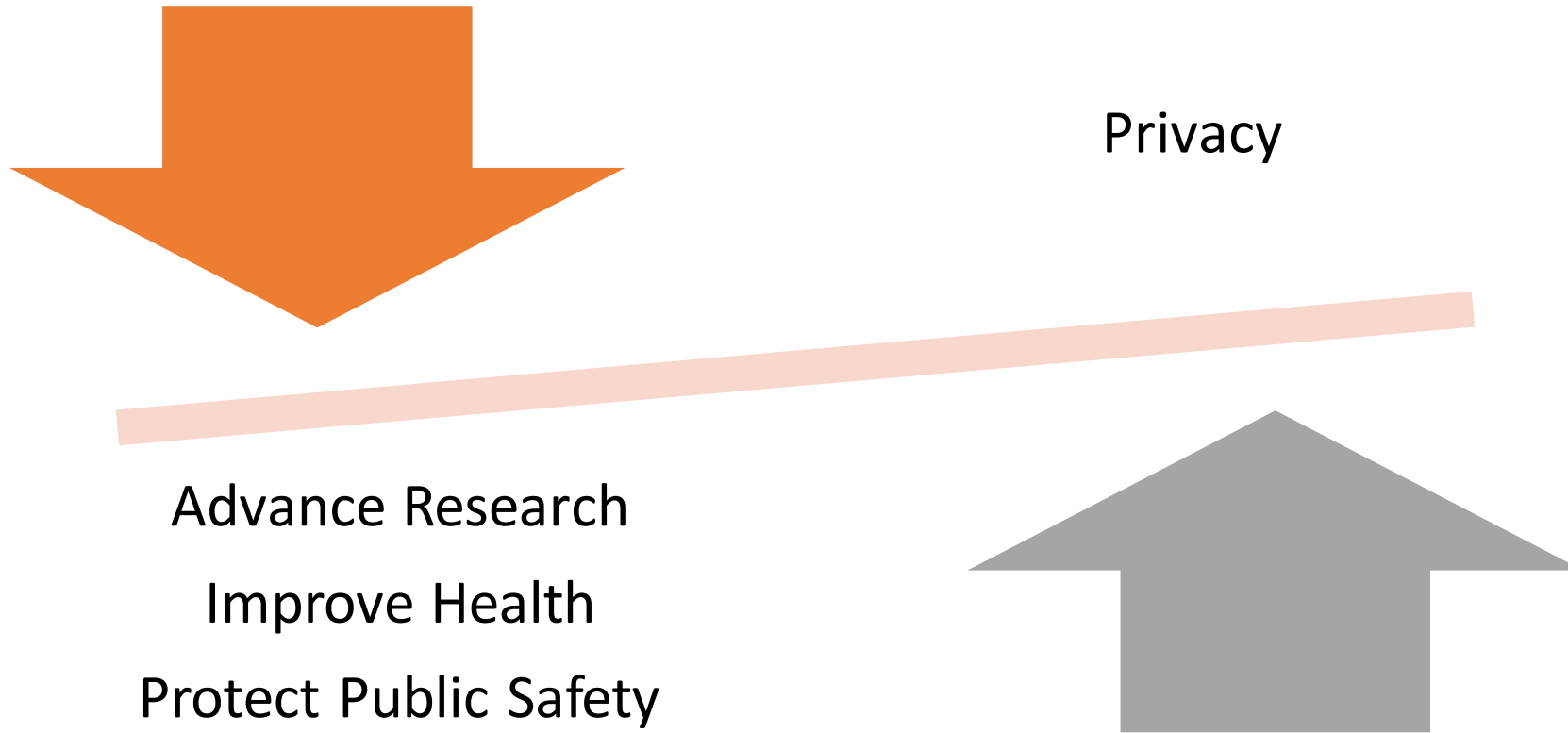
600+

Max Persons of Interest
tested in same 4 cases
prior to IGG (as a result
of other leads)

*Confidential source



Banbury Oct 19-21, 2019



It's all about trade-offs

Thank you

Diversity of Opinion on Appropriate Response

MD HB30 | 2019 | Regular Session



Maryland House Bill 30 (*Adjourned Sine Die*)

MD State Legislature page for HB30

[Summary](#) [Sponsors](#) [Texts](#) [Votes](#) [Research](#) [Comments](#) [Track](#)

POLICY FORUM | SCIENCE AND LAW

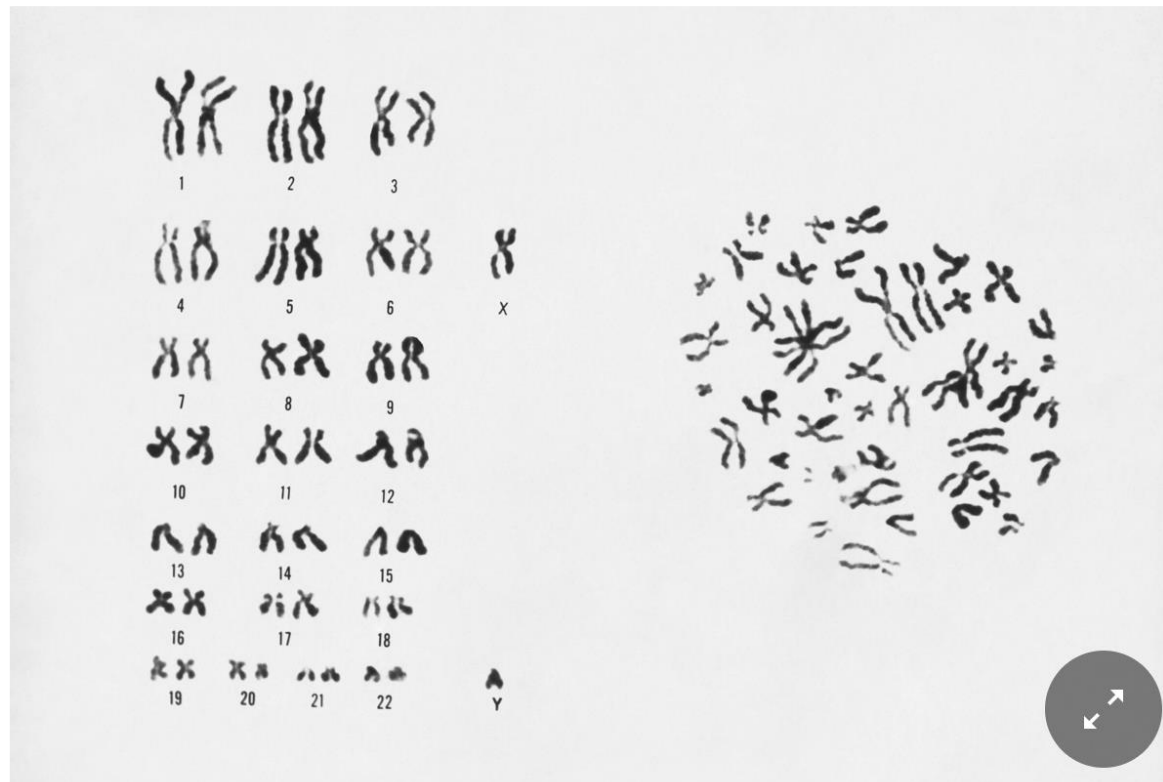
Is it time for a universal genetic forensic database?

J. W. Hazel^{1,2}, E. W. Clayton^{1,2,3}, B. A. Malin^{2,4,5,6}, C. Slobogin^{2,3}

+ See all authors and affiliations

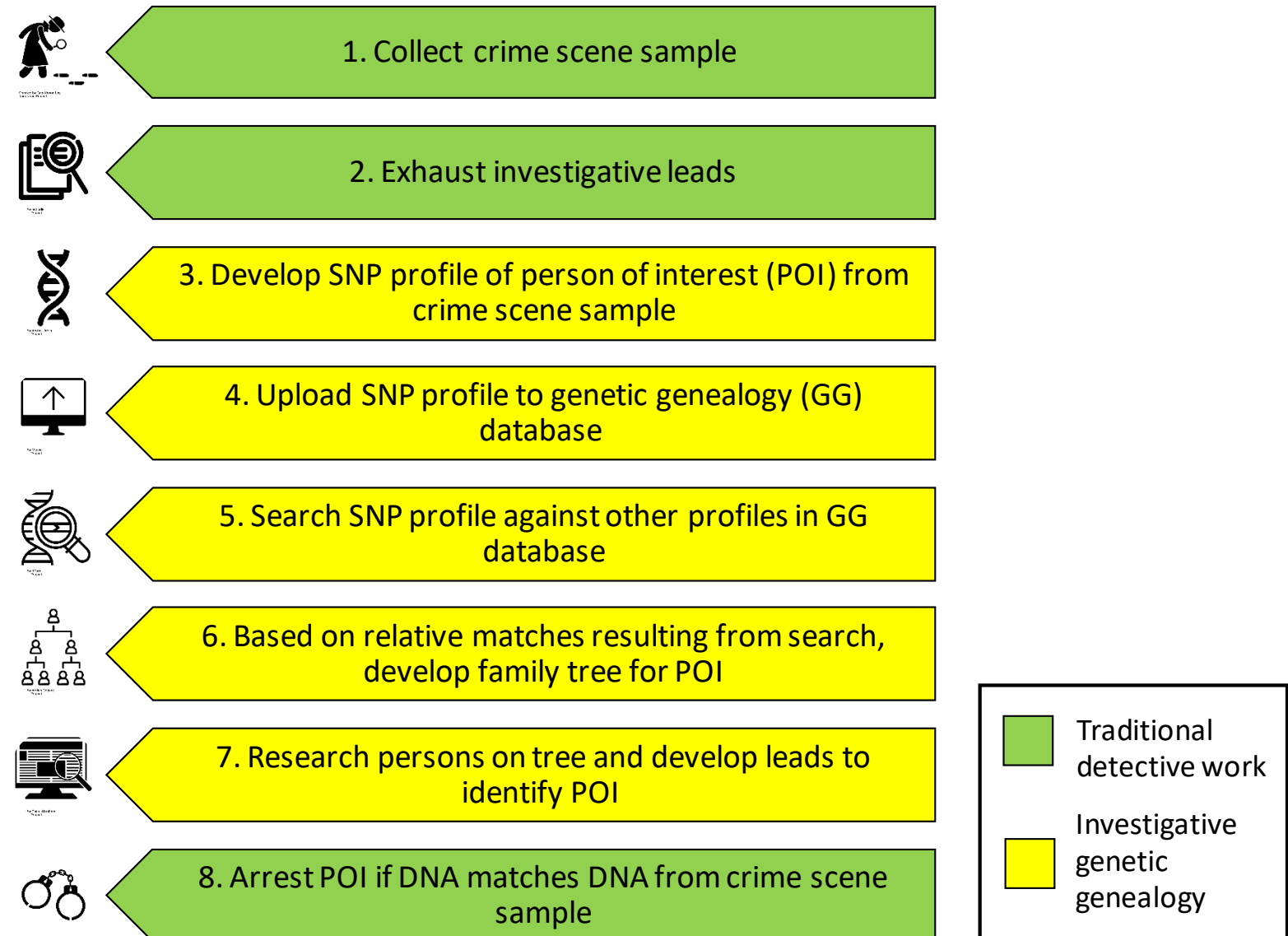
Science 23 Nov 2018:
Vol. 362, Issue 6417, pp. 898-900
DOI: 10.1126/science.aav5475

Most White Americans' DNA Can Be Identified Through Genealogy Databases

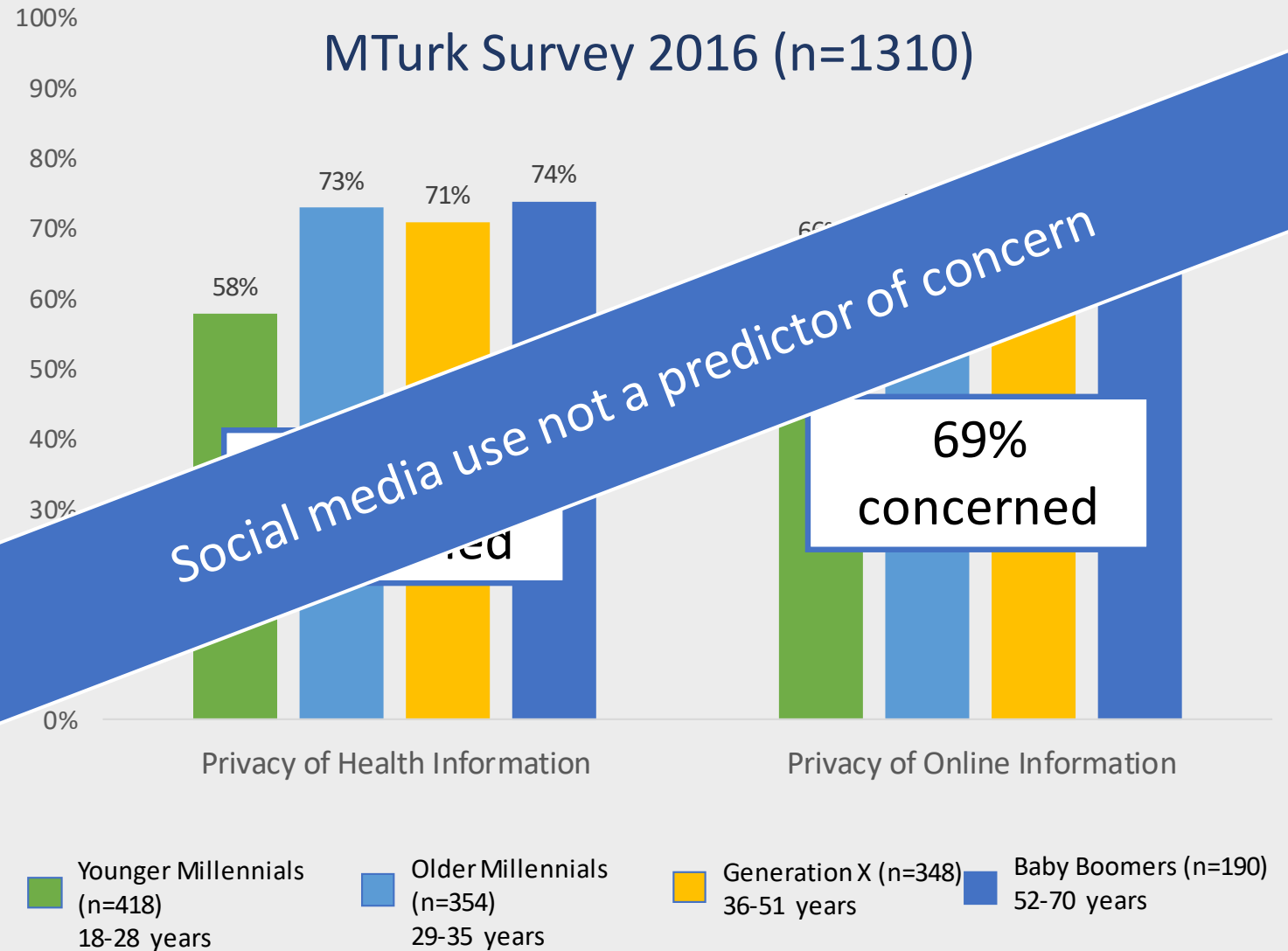


Only two percent of the population needs to have done a DNA test to identify nearly everyone else, researchers found. Leonard Lessin/Science Source

Fig. 1. Steps of IGG



Are people
like Sally
concerned
with their
privacy?



It's all about trade-offs

