Knowledge of DTC Genetic Testing Among the Public and Health Professionals

Presented by

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Public & Physician Awareness and Utilization of DTC Tests

- What is the public demand and interest in health-related DTC genetic tests?
- What do providers know & what is their experience with DTC genetic tests?
- What information is available to consumers about DTC genetic tests?
- How do consumers react to DTC testing information, and what is the impact on their health behavior?

National Surveys

- **HealthStyles,** National marketing survey conducted by Synovate, Inc.
  - Recruited from a consumer mail panel of ~450,000 potential respondents
  - **2006:** N = 5250 respondents; Response Rate: 66% (80%) for the first (second) phase
  - **2008:** N = 5399 respondents; Response Rate: 77% for the second phase
- **DocStyles**, Online survey of primary care physicians, internists, and pediatricians
  - Recruited from Epocrates Honor Panel, an opt-in, verified panel of 142,000 physicians
  - **2006:** N = 1250; Response Rate: 61% of eligible, invited physicians
  - **2008:** N = 1880; Response rate: 22%

2006 State BRFSS Surveys

- **CDC-funded State Programs in Public Health Genomics**
  - Oregon
  - Michigan
  - Utah
- **Behavioral Risk Factor Surveillance System (BRFSS)**
  - CDC-sponsored health survey system in all 50 states
  - Recruitment of adults through Random Digit Dialing
  - Response Rates: 51.7%, 52.4%, 63.4%

Results of Surveys

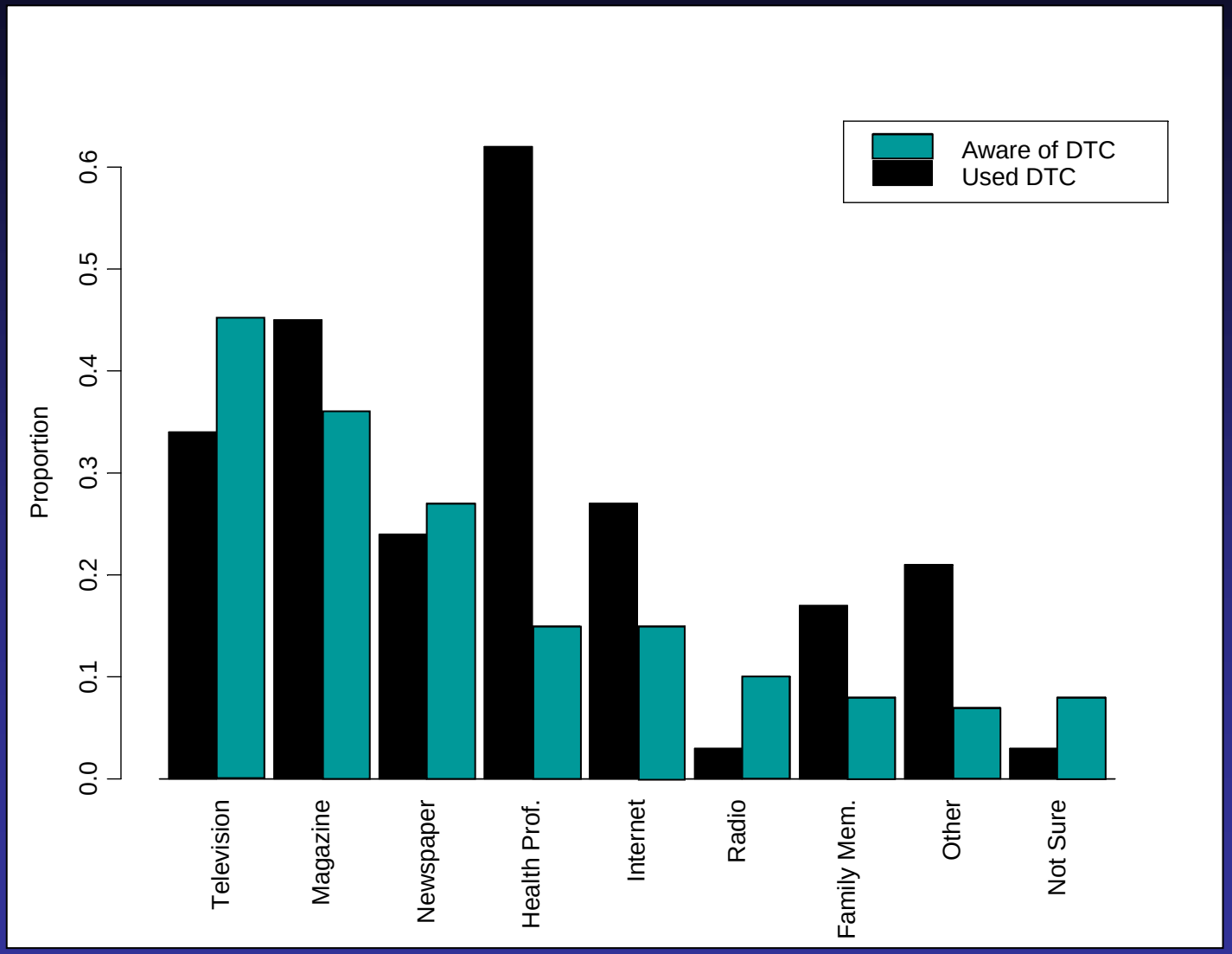
	Oregon	Michigan	Utah	National 2006	National 2008
Total Sample Size	1867	5499	2441	5250	5399
Awareness of DTC Tests (% Yes)	24.4%	7.6%	19.7%	14%	22%
Use of DTC Tests (% Yes)	0.3%	0.9%	-	0.6%	0.3%

Goddard et al., Genet in Med, 2007
Goddard et al., Am J Pub Health, 2009
Kolor et al., Genet in Med, 2009

Results of Surveys

	Oregon		Michigan		Utah		National	
Characteristic	%	p	%	p	%	p	%	p
Total Aware of DTC Tests	24.3		7.6		19.7		14	
Sex		.6602		.0394		.0548		.056
Race/Ethnicity		.1031		.7944		.4826		.066
Age, y		.0002		.0072		.0006		.0001
18–24	10.3		3.7		14.3		15	
25–34	20.3		7.6		15.3		17	
35–44	24.0		7.5		17.5		14	
45–54	27.8		9.7		26.9		15	
55–64	33.9		8.6		26.9		14	
65+	26.8		7.2		21.4		9	
Household income		.0308		<.0001		.0735		.0001
Low	21.6		4.7		14.2		11	
Intermediate	21.4		6.6		18.8		13	
High	28.2		9.5		21.4		16	
Education level		.0001		<.0001		<.0001		<.0001
High school or less	16.3		5.2		13.1		9	
At least some college	25.4		6.9		18.1		15	
College graduate*	33.0		11.6		28.6		19	

Consumer Sources of Information on DTC Genetic Testing



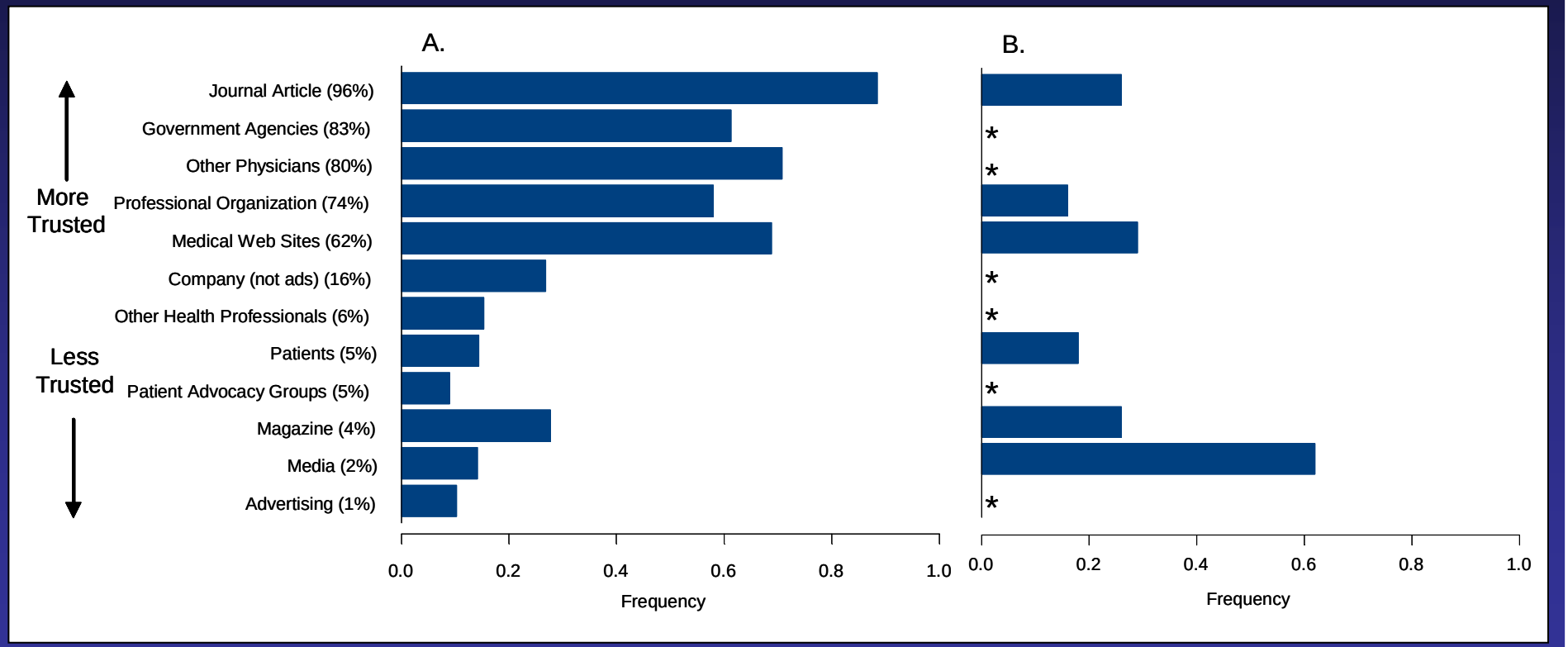
73% of respondents heard/read about DTC genetic tests through the media

DocStyles Survey

Characteristic	DocStyles 2006 (50% Aware)	DocStyles 2008 (42% Aware)
Specialty	.042	+
Work setting	.098	+
Sex	.008	
Age	.676	+
Number of patients per week	.837	
Number of years of practice	.441	

Goddard et al., Genet in Med, 2007
Kolor et al., Genet in Med, 2009

Physician Sources of Information



What information is available to consumers about DTC genetic tests?

Example: Genetic Tests for Thrombosis Risk

"The Web sites use simplified language that tends to broaden the class of persons for whom testing is indicated."

The Website(s)	The Recommendation(s)
'individuals with any family member with venous thromboembolism (VTE)'	'relatives of individuals with venous thrombosis under age 50'
'women with premature MI'	'female smokers younger than age 50 years with a MI or stroke'
'a personal history of VTE'	'a first VTE before age 50 years'

Goddard et al., *Public Health Genomics, 2009*

Indications For Testing

Indications[a]	ACMG[b]	CAP[c]	DTC company[d]				
			A	B	C	E	F
A first VTE before age 50 years	S	S	–	S	–	–	–
A first unprovoked VTE at any age	–	S	–	–	–	–	–
A history of recurrent VTE	S	S	–	S	–	–	–
Venous thrombosis at unusual sites	S	S	–	S	–	–	–
VTE during pregnancy	S	S	–	S	–	–	–
VTE during the puerperium	–	S	–	S	–	–	–
VTE associated with use of OC	S	S	–	S	–	–	–
VTE associated with HRT	–	S	–	M	–	–	–
Relatives of individuals with venous thrombosis under age 50	S	–	–	–	–	–	–
A first VTE in an individual with a first degree family member with VTE before age 50	S[e]	S	–	S[e]	–	–	–
Women with unexplained fetal loss after 10 weeks gestation	M	S	–	–	S	–	–
Female smokers younger than age 50 years with an MI or stroke	S	M	–	–	–	–	–
Individuals with any family member with VTE	–	–	S	M	S	–	S
Anyone	–	–	M	–	–	–	–
Personal history of VTE	–	–	–	–	S	–	S
Personal history of pulmonary embolism	–	–	–	–	S	–	S
Personal history of TIA or premature stroke	–	–	–	–	S	–	S
Personal history of peripheral vascular disease	–	–	–	–	S	–	–
Personal history of cerebral vein thrombosis	–	–	–	–	S	–	S
Women with premature MI	–	–	–	–	S	–	S
Prior to major surgery, pregnancy, OC use, or HRT if there is a personal or family history of thrombosis	–	–	–	M	S	–	–
Presence of another known genetic hypercoagulability in an individual with a history of thrombosis	–	–	–	–	S	–	–
Previous finding of activated protein C resistance by lab analysis	–	–	–	–	S	–	–

Goddard, *Public Health Genomics*, 2009

Benefits/Risks of Testing

	ACMG[b]	CAP[c]	DTC company[d]				
			A	B	C	E	F
Benefits of factor V Leiden testing[a]							
identification of high-risk patients who could benefit from long-term anticoagulant therapy	+	+	–	–	–	–	–
identification of high-risk patients who could benefit from aggressive prophylaxis in temporary periods of high thrombotic risk	+	+	–	–	–	–	–
opportunity to counsel at-risk family members about risks, signs, and symptoms of VTE	+	+	–	–	–	–	–
future decisions regarding HRT could depend on genotype	–	+	–	+	–	–	–
future decisions regarding management of pregnancy complications could depend on genotype	+	+	–	+	–	–	–
future decisions regarding OC use could depend on genotype	+	+	–	+	–	–	–
to have greater control over your health care	–	–	+	+	–	–	–
to provide you with tools to live a longer, healthier life	–	–	+	–	–	–	–
future decisions regarding health-enhancing strategies could depend on genotype	–	–	+	–	–	–	–
future decisions regarding lifestyle changes could depend on genotype	–	–	+	+	–	–	–
provide a customized risk assessment	–	–	+	+	–	–	–

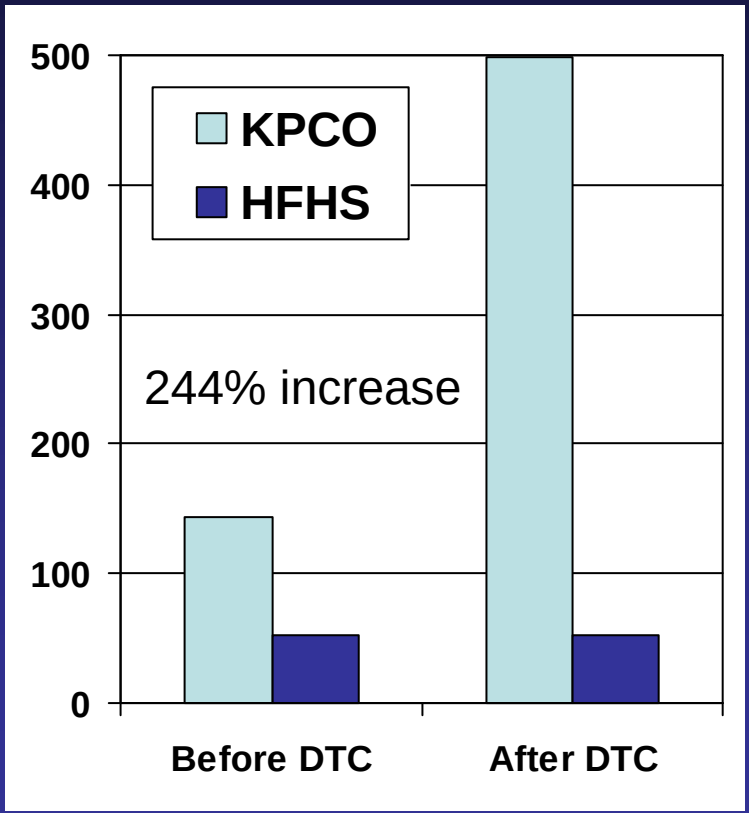
Goddard, *Public Health Genomics*, 2009

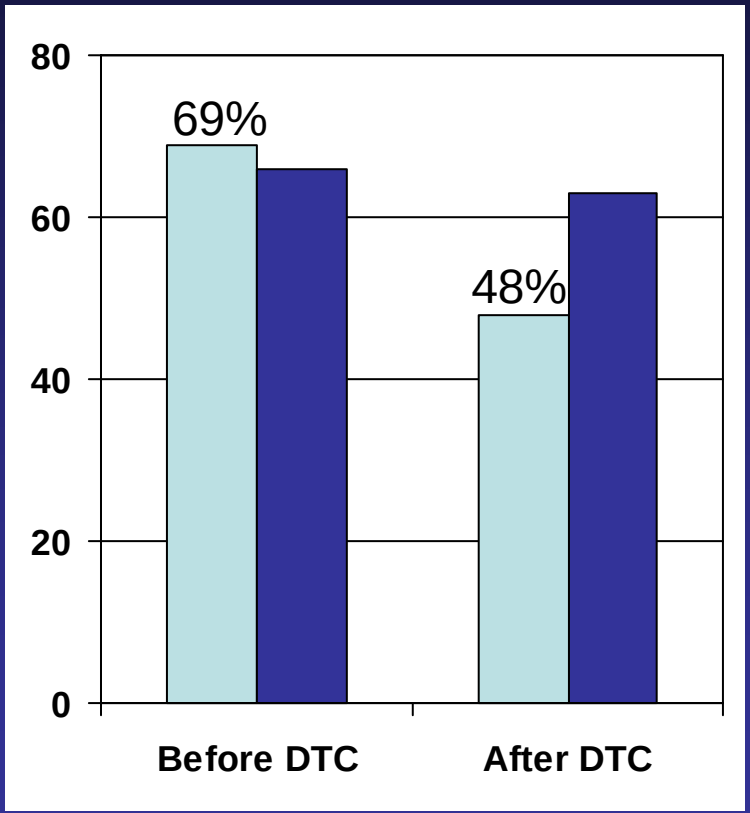
Impact of Risk Information on Health Behavior

Outcome Measure	No risk (%)	Unattributed Risk (%)	Expert Risk (%)	OR (95% CI)	P-value
Intend to get BRCA testing	30	15	19	.48 (.26-.87)	.016
Positive beliefs about Internet testing	33	21	17	.48 (.27-.86)	.014
Preference for clinical testing	62	67	77	1.53 (.90-2.62)	.117
Trust in internet testing	64	59	71	1.06 (.63-1.82)	.813
Believe internet testing is wise	43	34	37	.73 (.44-1.22)	.234
Sites provide enough risk information	63	70	67	1.27 (.75-2.17)	.371

Gray, *Cancer Epidemiol Biomarkers Prev,* 2009

BRCA Example: DTC advertising increases uptake of BRCA testing among *both* eligible and ineligible candidates





Mouchawar, *Genet in Med,* 2005

Conclusions

- Only a small percentage of the U.S. population is aware of or has used DTC Genetic Tests
- The media is the most frequent source of information for both consumers and physicians
- DTC websites often do not provide information on indications or risks/benefits of testing.
- The presentation of risk information may influence consumer's beliefs and possibly their behavior.

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