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Phyllis Brawarsky

Katjuska Eibensteiner

Elissa V Klinger

Heather J Baer

George Getty

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Authors

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To cite this article: Phyllis Brawarsky, Katyuska Eibensteiner, Elissa V. Klinger, Heather J. Baer, George Getty, E. John Orav, Graham Colditz & Jennifer S. Haas | (2018) Accuracy of self-perceived risk for common conditions, Cogent Medicine, 5:1, 1463894, DOI: [10.1080/2331205X.2018.1463894](https://doi.org/10.1080/2331205X.2018.1463894)

To link to this article: <https://doi.org/10.1080/2331205X.2018.1463894>



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Published online: 23 Apr 2018.



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Received: 03 November 2017
Accepted: 08 April 2018
First Published: 16 April 2018

*Corresponding author: Jennifer S. Haas, Division of General Medicine and Primary Care, Brigham and Women's Hospital, 1620 Tremont Street, Boston, MA 02120, USA; Department of Medicine, Harvard Medical School, USA; Departments of Epidemiology and Social and Behavioral Sciences, Harvard TH Chan School of Public Health, USA
E-mail: jhaas@bwh.harvard.edu

Reviewing editor:
Rahman Shiri, Finnish Institute of Occupational Health, Finland

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PUBLIC HEALTH | RESEARCH ARTICLE

Accuracy of self-perceived risk for common conditions

Phyllis Brawarsky¹, Katyuska Eibensteiner¹, Elissa V. Klinger¹, Heather J. Baer^{1,2,3}, George Getty¹, E. John Orav¹, Graham Colditz⁴ and Jennifer S. Haas^{1,2,3*}

Abstract: *Background:* Accurate awareness of common disease risk is necessary to promote healthy lifestyles and to prevent unnecessary anxiety and evaluation. Our objective is to identify characteristics of patients who do not accurately perceive their risk of developing coronary heart disease (CHD), diabetes (DM), breast cancer (BC) and colorectal cancer (CRC). *Methods:* Using personalized disease risk reports and risk perception surveys, subjects ($n = 4703$) were classified as high or low/average risk and high or low/average perceived risk for each condition. Models were used to examine factors associated with risk under-estimation by high risk patients and risk over-estimation by low/average risk patients. *Results:* Patients at high risk for DM, BC and CRC often (60–75% of the time) under-estimated their risk, while low/average risk patients overestimated their risk 13–40% of the time. For CHD, under-estimation by high risk individuals approximated over-estimation by low/average individuals. Compared to normal weight patients at high risk for cancer, obese patients were more likely to under-estimate their risk for BC (OR 3.1, CI 1.9–5.0) and CRC (2.6, 1.5–4.5) as were overweight patients. Overweight and obese patients at low/average risk of DM or CHD were more likely than normal weight patients to over-estimate their risk. Low/average risk women were more likely than men to over-estimate their risk of DM (1.3, 1.1–1.5) and CHD (1.8, 1.5–2.1). *Conclusions:* Our data show that body mass index is the factor most consistently associated with incorrect risk perceptions for several common conditions.

ABOUT THE AUTHORS

Jennifer Haas, MD, MSc, is a professor of Medicine in the Division of General Internal Medicine and Primary Care at Brigham and Women's Hospital and Harvard Medical School, and in the Department of Social and Behavioral Sciences at the Harvard TH Chan School of Public Health. Haas focuses on how to use systems-based interventions to improve the use of screening and prevention in primary care and how health information technology can improve the flow of information between patients and providers.

PUBLIC INTEREST STATEMENT

Accurate understanding of a person's risk of developing common diseases, like heart disease, diabetes, breast and colon cancer, is needed to encourage healthy lifestyle behaviors and to prevent unnecessary anxiety and evaluation. This study compares a person's beliefs about their risk of developing these common diseases to their risk estimated from their characteristics and risk factors. We find that it is common (60 to 75% of the time) for high risk individuals to under-estimate their risk, while low/average risk patients overestimate their risk 13–40% of the time. Accurate risk estimation varies by gender, and body mass index is associated with incorrect risk perceptions for several common conditions.

Subjects: Risk Communication; General Medicine; Primary Health Care & Family Practice

Keywords: perceived risk; calculated risk; coronary heart disease; diabetes; breast cancer; colorectal cancer

1. Introduction

Non-communicable diseases such as cardiovascular diseases, diabetes, and cancer, are the leading cause of death globally, and are the main drivers of morbidity, and health-care costs in the US (Bauer, Briss, Goodman, & Bowman, 2014). Patients' perception of their actual risk of disease or the belief in the probability that they will experience an adverse event is important regardless of actual risk for developing these diseases (Lavielle & Wacher, 2014; Leite-Pereira, Medeiros, & Dinis-Ribeiro, 2011). For those at high risk, an accurate understanding of risk can help patients identify and adopt relevant lifestyle changes and adherence to preventive interventions (e.g. early or more intensive screening, pharmacologic treatment, prophylactic surgery) that can lead to a better health-related quality of life (Cainzos-Achirica & Blaha, 2015; Dieng et al., 2014; Fagan, Sifri, Wender, Schumacher, & Reed, 2012; Leite-Pereira et al., 2011; Wang et al., 2009). For those at low or average risk, accurate risk perception can help patients reduce anxiety and avoid unnecessary intervention (Haas et al., 2005).

Previous research has shown that patients overall and individuals both at high or low/ average risk for these diseases do not correctly perceive their risk (Cainzos-Achirica & Blaha, 2015; Everett, Salamonson, Rolley, & Davidson, 2016; Fagan et al., 2012; Leite-Pereira et al., 2011; van der Weijden, Bos, & Koelewijn-van Loon, 2008; Wang et al., 2009). For example, overweight and obese patients may not perceive they are at higher risk for colorectal cancer (CRC);(Fagan et al., 2012) patients at high risk for diabetes (DM) or heart disease (CHD) are often not aware of this risk; (Adriaanse et al., 2008; Darlow, Goodman, Stafford, Lachance, & Kaphingst, 2012) many women both over-estimate or under-estimate their risk of breast cancer BC (de Jonge, Vlasselaer, Van de Putte, & Schobbens, 2009; Erblich, Bovbjerg, Norman, Valdimarsdottir, & Montgomery, 2000; Haas et al., 2005). Prior work has focused on examining risk perceptions for specific conditions. We are not aware of prior studies that have looked at risk perceptions across cancers and other common conditions, stratified by patients' actual risk of these diseases.

The goal of this analysis is to identify demographic characteristics of patients at low/ average risk who over-estimate their risk and those at high risk who under-estimate their risks of CHD, DM, BC and CRC.

2. Methods

2.1. Overview

The Patient Risk Evaluation and Prevention (PREP) study was a cluster randomized controlled trial (RCT) of adult primary care patients receiving care in the Brigham and Women's Primary Care Practice-Based Research Network (NCT01468675) (Haas et al., 2017). A goal of PREP was to assess whether patients' receipt of a personalized disease risk report prior to a primary care visit was associated with improved patient-provider communication about disease risk. Patients in intervention clinics completed a detailed survey about their family history, lifestyle, and risk perceptions and received a personalized risk report based on *Your Health Snapshot (YHS)*, a self-administered health risk assessment derived from validated algorithms of *Your Disease Risk* (www.yourdiseaserisk.wustl.edu) (Colditz et al., 2000; Kim, Rockhill, & Colditz, 2004). Risk factors inputs for the algorithms were obtained from the survey responses and data from the electronic health record (EHR) prior to the visit. Patients in the control clinics completed a short survey about risk perceptions before their visit. After their visit, they completed the detailed survey and received a personal risk report. Risk reports presented calculated risk, summarized as low or average vs. high risk, for CHD, DM, CRC and BC

(women only) for patients who did not already have a specific condition (Colditz et al., 2000; Kim, Rockhill, & Colditz, 2004). For example, a woman who had already been diagnosed with CHD would not be asked about her risk of developing CHD, but would be asked about her risk for the other 3 conditions. Risk perception questions asked separately for each condition whether compared to an average person of the same age, an individual believed that he/ she was more likely, less likely or about as likely to get the condition (“Compared to the average person your age, would you say that you are more likely to get {condition}, less likely, or about as likely?”) We conducted a secondary analysis of data collected from PREP to identify demographic characteristics of patients who do not accurately perceive their risk of developing CHD, DM, BC and CRC, so that appropriate interventions can be developed.

2.2. Data analysis

We included participants, irrespective of intervention status, who answered the pre-visit risk perception questions and received a risk report (intervention arm received pre-visit, control arm received post-visit). For the purposes of this analysis, we combined low or average calculated and perceived risk into a category of low/average risk (i.e. not high). Among those categorized as low/average calculated risk, the percent that was low risk compared to average risk was 88% for DM, 93% for CHD, 50% for BC and 59% for CRC. Additional patient data, obtained from the EHR, included age, sex, race, education, ethnicity, marital status, insurance, body mass index (BMI), smoking status, prior personal history of CHD, DM, BC or CRC and Charlson comorbidity score (Charlson, Pompei, Ales, & MacKenzie, 1987). For each of the conditions, we used logistic regression models to examine the demographic factors associated with high risk patients who under-estimated their risk and low/average risk patients who over-estimated their risk. Statistical analyses were conducted using SAS version 9.2 (Cary, NC) with $p < 0.05$ as the criterion for statistical significance.

3. Results

3.1. Study population

Overall, the mean age of participants was 54 years, 75.5% were female, 5.8% were Latino, and 5.1% were black (Table 1). Almost 26% of participants were obese and 3.5% were current smokers. Approximately 70% had college or higher education degrees and 74% had private insurance. Fifteen percent were at high risk for developing CRC, 19.5% for breast cancer, 16.8% for DM, and 6.7% for CHD.

Among patients at low/average risk for disease, the percentage who over-estimated their perceived risk of disease, ranged from 13% for CRC to 56% for CHD (Table 2). Women were more likely than men to overestimate their risk of diabetes (1.3, 1.1–1.5) and CHD (1.8, 1.5–2.1). Compared to normal weight patients (BMI 18.5–24.9 kg/m²), overweight patients (BMI 25–29.9) were more likely to overestimate their risk of DM (1.6, 1.3–1.8) and CHD (1.5, 1.3–1.8), but less likely to overestimate their risk of BC (0.6, 0.5–0.8) and CRC (0.9, 0.7–1.0). The same was true for obese patients (BMI ≥ 30). Compared to whites, blacks were also more likely to over-estimate their risk for DM and less likely to overestimate their risk for CRC. Patients age 45–75 were less likely to over-estimate risk of DM and BC compared to younger patients.

Among patients at high risk for disease, self-perceived under-estimation ranged from 57% for CHD to 75% for CRC (Table 3). Overweight and obese patients were more likely than normal weight patients to under-estimate their risk for BC (1.7, 1.1–2.8; 3.1, 1.9–5.0 respectively) and to under-estimate their risk for CRC (1.8, 1.0–3.3; 2.6, 1.5–4.5, respectively). Compared to whites, Hispanics were less likely to underestimate their risk for diabetes (0.4, 0.2–0.8).

Table 1. Characteristics of participants

	N (%)
Overall N = 4,703	
Age in years, mean (SD)	53.6 (11.8)
Sex	
Female	3,549 (75.5)
<i>Race/ethnicity</i>	
White	39.59 (84.2)
Black	238 (5.1)
Latino	271 (5.8)
Other/unknown	235 (5.0)
<i>Marital status</i>	
Married or living with partner	3,234 (68.8)
<i>Insurance</i>	
Private	3,460 (73.6)
Medicare	937 (19.9)
Medicaid	306 (6.5)
<i>BMI category</i>	
Normal/underweight	1,866 (39.7)
Overweight	1,627 (34.6)
Obese	1,206 (25.6)
<i>Smoking status</i>	
Current	163 (3.5)
Former	1,556 (33.2)
Never	2,971 (63.3)
<i>Education</i>	
College graduate or higher	3,273(69.6)
Some college	614 (13.1)
High school graduate or less	431 (9.2)
Other/don't know	385 (8.2)
<i>Prior personal history of</i>	
Colon cancer	51 (1.1)
Breast cancer (women only)	268 (7.6)
Diabetes	349 (7.4)
CHD	334 (7.1)
<i>Mean Charlson comorbidity score (range)</i>	
0	4,234 (90.0)
1	275 (5.9)
2,3	194 (4.1)
<i>High risk for developing¹</i>	
Colon cancer	645 (14.9)
Breast cancer (women only)	597 (19.5)
Diabetes	680 (16.8)
CHD	270 (6.7)

¹The denominator includes those subjects who had both a risk report and answer to the risk perception question. The denominators are: 4,339 for colon cancer, 3,055 for breast cancer, 4,041 for diabetes and 4,037 for CHD. Percentages may not add to 100% because of rounding.

Table 2. Patients with low/average risk who over-estimate risk by disease

	Diabetes ¹		CHD ¹		Breast cancer (Female only) ²		Colon cancer ¹	
	No. (%)	OR (CI)	No. (%)	OR (CI)	No. (%)	OR (CI)	No. (%)	OR (CI)
Overall	1,304 (38.8)		2,093 (55.6)		788 (32.1)		1,482 (13.0)	
<i>Age (years)</i>								
30–44	334 (42.8)	reference	518 (57.0)	reference	283 (42.8)	reference	365 (42.9)	reference
45–59	566 (40.1)	0.8 (0.7–1.0)	922 (57.3)	1.0 (0.8–1.2)	346 (33.1)	0.6 (0.5–0.8)	623 (41.2)	0.9 (0.8–1.1)
60–75	404 (34.5)	0.7 (0.6–0.9)	653 (52.2)	0.9 (0.7–1.1)	159 (21.2)	0.3 (0.2–0.4)	494 (37.1)	0.9 (0.7–1.1)
<i>p</i> value χ^2	0.0004		0.0157		<.0001		0.0136	
<i>Sex</i>								
Female	997 (39.5)	1.3 (1.1–1.5)	1713 (58.0)	1.8 (1.5–2.1)			1134 (41.1)	1.1 (0.9–1.3)
Male	307 (36.6)	reference	380 (46.7)	reference			348 (37.1)	reference
<i>p</i> value χ^2	0.1340		<.0001				0.0313	
<i>BMI</i>								
Normal/underweight	585 (34.8)	reference	826 (50.0)	reference	485 (40.1)	reference	763 (46.6)	reference
Overweight	582 (43.8)	1.6 (1.3–1.8)	769 (57.7)	1.5 (1.3–1.8)	215 (29.9)	0.6 (0.5–0.8)	581 (41.8)	0.9 (0.7–1.0)
Obese	137 (38.7)	1.2 (1.0–1.6)	498 (63.7)	1.8 (1.5–2.2)	88 (16.6)	0.3 (0.2–0.4)	138 (20.8)	0.3 (0.3–0.4)
<i>p</i> value χ^2	<.0001		<.0001		<.0001		<.0001	
<i>Race</i>								
White	1,126 (37.9)	reference	1,805 (55.4)	reference	652 (32.0)	reference	1,315 (41.1)	reference
Black	47 (49.5)	1.5 (1.0–2.2)	82 (56.6)	0.9 (0.6–1.3)	30 (23.4)	0.8 (0.5–1.3)	38 (27.1)	0.7 (0.5–1.0)
Hispanic	48 (42.9)	1.0 (0.6–1.5)	100 (59.2)	1.2 (0.9–1.7)	54 (34.8)	1.1 (0.7–1.6)	54 (33.5)	0.9 (0.6–1.3)
Other/DK	83 (45.6)	1.4 (1.0–1.9)	106 (54.1)	1.0 (0.7–1.3)	52 (37.7)	1.0 (0.7–1.5)	75 (39.5)	0.8 (0.6–1.1)
<i>p</i> value χ^2	0.0187		0.7634		0.0744		0.0030	
<i>Insurance</i>								
Private	1,031 (39.6)	reference	1,670 (57.1)	reference	642 (34.0)	reference	1,171 (41.9)	reference
Medicare	200 (33.4)	0.9 (0.7–1.2)	322 (51.0)	0.8 (0.7–1.0)	90 (22.9)	1.1 (0.8–1.5)	248 (35.2)	0.9 (0.7–1.1)
Medicaid	73 (44.8)	1.2 (0.8–1.7)	101 (48.1)	0.6 (0.4–0.8)	56 (32.2)	0.9 (0.6–1.3)	63 (32.0)	0.8 (0.6–1.1)
<i>p</i> value χ^2	0.0049		0.0018		0.0001		0.0003	
<i>Education</i>								
HS grad or less	87 (44.2)	1.2 (0.9–1.7)	144 (56.0)	1.0 (0.7–1.3)	67 (30.9)	1.4 (1.0–2.0)	89 (33.0)	0.9 (0.7–1.2)
Some college	149 (38.4)	1.0 (0.8–1.3)	268 (59.2)	1.1 (0.9–1.3)	109 (31.7)	1.3 (1.0–1.6)	166 (37.9)	1.0 (0.8–1.2)
College grad or higher	958 (38.2)	reference	1,514 (55.1)	reference	543 (32.1)	reference	1,110 (41.4)	reference
Other/DK	110 (40.3)	1.0 (0.8–1.3)	167 (53.4)	0.9 (0.7–1.2)	69 (34.0)	1.2 (0.9–1.7)	117 (38.2)	0.9 (0.7–1.2)
<i>p</i> value χ^2	0.3925		0.3617		0.9169		0.0295	

¹Models adjusted for education, smoking status, BMI, sex, race/ethnicity, insurance, age, marital status, Charlson category and group (intervention or control).

²Model adjusted for all variables listed above except sex.

4. Discussion

Accurate awareness of common disease risk in both high and low/average risk persons is an important factor in promoting positive lifestyle and behaviors and preventing unnecessary interventions, anxiety and screenings. To our knowledge, ours is the first study to compare risk perceptions of patients, stratified by risk, to actual risk across several common conditions. We found that overall, except for CHD where approximately 55% of both high and low risk patients incorrectly estimated risk, high risk patients often (60 to 75% of the time) under-estimated their risk, while low/average risk

Table 3. Patients with high risk patients who under-estimate risk by disease

	Diabetes ¹		CHD ¹		Breast cancer (Female only) ²		Colon cancer ¹	
	No. (%)	OR (CI)	No. (%)	OR (CI)	No. (%)	OR (CI)	No. (%)	OR (CI)
Overall	409 (60.1)		155 (57.4)		433 (72.5)		481 (74.6)	
<i>Age (years)</i>								
30–44	82 (52.9)	reference	22 (53.7)	reference	73 (67.6)	reference	99 (81.8)	reference
45–59	160 (55.6)	1.0 (0.7–1.5)	62 (53.5)	1.2 (0.6–2.5)	177 (70.0)	1.2 (0.7–2.1)	213 (74.2)	0.7 (0.4–1.2)
60–75	167 (70.5)	1.7 (1.0–2.8)	71 (62.8)	1.3 (0.6–3.1)	183 (77.9)	1.4 (0.8–2.5)	169 (71.3)	0.7 (0.4–1.2)
<i>p</i> value χ^2	0.0003		0.3105		0.0573		0.0953	
<i>Sex</i>								
Female	311 (58.0)	0.7 (0.4–1.0)	84 (53.9)	0.7 (0.4–1.3)		366 (74.0)	0.8 (0.5–1.3)	
Male	98 (68.1)	reference	71 (62.3)	reference		115 (76.1)	reference	
<i>p</i> value χ^2	0.0290		0.1663			0.6092		
<i>BMI</i>								
Normal/underweight	12 (80.0)	reference	7 (70)	reference	111 (61.3)	reference	48 (59.3)	reference
Overweight	71 (71.7)	0.6 (0.1–2.3)	31 (56.4)	0.5 (0.1–2.5)	138 (72.3)	1.7 (1.1–2.8)	89 (70.1)	1.8 (1.0–3.3)
Obese	326 (57.6)	0.3 (0.1–1.0)	117 (57.1)	0.5 (0.1–2.3)	184 (81.8)	3.1 (1.9–5.0)	344 (78.7)	2.6 (1.5–4.5)
<i>p</i> value χ^2	.0085		0.7109		<.0001		0.0005	
<i>Race</i>								
White	327 (62.6)	reference	116 (56.3)	reference	396 (73.6)	reference	373 (73.1)	reference
Black	33 (52.4)	0.7 (0.4–1.2)	15 (57.7)	1.3 (0.5–3.1)	16 (72.7)	0.7 (0.3–2.1)	47 (85.5)	1.9 (0.8–4.3)
Hispanic	34 (46.6)	0.4 (0.2–0.8)	20 (64.5)	2.1 (0.8–5.3)	11 (61.1)	0.6 (0.2–1.9)	41 (75.9)	1.1 (0.5–2.3)
Other/DK	15 (68.2)	1.0 (0.4–2.6)	4 (57.1)	1.4 (0.3–7.1)	10 (52.6)	0.5 (0.2–1.4)	20 (76.9)	1.4 (0.5–3.9)
<i>p</i> value χ^2	0.0274		0.8630		0.1533		0.2491	
<i>Insurance</i>								
Private	275 (57.8)	reference	94 (53.7)	reference	311 (70.5)	reference	338 (76.6)	reference
Medicare	99 (70.2)	1.4 (0.8–2.2)	46 (67.7)	2.0 (1.0–4.2)	108 (81.2)	1.6 (0.8–2.9)	99 (69.7)	0.7 (0.4–1.1)
Medicaid	35 (55.5)	1.3 (0.7–2.4)	15 (55.6)	1.0 (0.4–2.6)	14 (60.9)	0.7 (0.2–1.9)	44 (71.0)	0.5 (0.3–1.1)
<i>p</i> value χ^2	0.0220		0.1402		0.0237		0.2032	
<i>Education</i>								
HS grad or less	59 (61.5)	1.4 (0.8–2.3)	28 (56.0)	0.9 (0.4–1.8)	28 (73.7)	1.2 (0.5–3.1)	69 (79.3)	1.3 (0.7–2.5)
Some college	74 (58.7)	1.3 (0.8–2.0)	27 (52.9)	0.7 (0.3–1.4)	60 (74.1)	1.0 (0.6–1.8)	93 (75.0)	1.1 (0.7–1.8)
College grad or higher	233 (58.5)	reference	89 (61.8)	reference	311 (72.7)	reference	283 (73.7)	reference
Other/DK	43 (71.7)	2.1 (1.1–4.0)	11 (44.0)	0.5 (0.2–1.4)	34 (68.0)	1.0 (0.5–1.9)	36 (72)	1.0 (0.5–2.1)
<i>p</i> value χ^2	0.2699		0.3295		0.8870		0.7123	

¹Models adjusted for education, smoking status, BMI, sex, race/ethnicity, insurance, age, marital status, Charlson category and group (intervention or control).

²Model adjusted for all variables listed above except sex.

patients overestimated their risk of these conditions 13–40% of the time. We found BMI to be the demographic factor most consistently associated with incorrect risk perceptions. Patients who were overweight or obese, and who were at high risk for BC or CRC were more likely to under-estimate their risks of these cancers. Although obesity has been shown to be a risk factor for CRC and for BC among post-menopausal women (Bhaskaran et al., 2014; Leite-Pereira et al., 2011; Renehan & Soerjomataram, 2016), studies have also shown that knowledge of obesity as a risk factor for cancer, including CRC and BC, is low (Consedine, Magai, Conway, & Neugut, 2004; Fagan et al., 2012;

Leite-Pereira et al., 2011). In particular, a previous study found that even with the understanding that behavioral factors can reduce cancer risk, many subjects, including those who were obese, did not consider overweight as an important risk factor for cancer (Cameron et al., 2010). Further, weight perceptions can be inaccurate (Squiers et al., 2014). Given the high prevalence of obesity in the US (Ogden, Carroll, Fryar, & Flegal, 2015), these results underscore the need for health education programs targeted to overweight and obese persons which stress weight as a modifiable cancer risk and the importance of appropriate cancer screenings. In addition, studies are needed determine how such education programs can be most effective.

We also found that overweight and obese patients at low/average risk for CHD and DM were more likely to over-estimate their risks of these diseases. This finding is consistent with prior studies which found obese people in general over-estimate DM, CHD risks (Darlow et al., 2012; van der Weijden et al., 2008; Winter & Wuppermann, 2014), and suggests an understanding of weight as a significant risk factor for these diseases, even if other risk factors are not present. However, a disadvantage of over-estimation can be over-prescription of medications where harms may outweigh benefits. In addition, we note that although heightened risk perception may lead to an increase in preventive behavior, studies have also shown that awareness alone does not motivate behavior (Alzaman, Wartak, Friderici, & Rothberg, 2013; Lavielle & Wacher, 2014).

A limitation of this study is that PREP only reached 20% of potentially eligible individuals; most of our population was white and of higher socioeconomic status. It is possible that individuals who participated are more “health conscious,” as indicated by our low percentage of current smokers. Therefore, our study may include fewer high risk individuals compared to the general population of patients seen in primary care settings. However, we are not comparing low risk to high risk individuals, and our sample size is robust for both high risk and low risk patients across the demographic factors.

In conclusion, for those at high risk of developing BC, CRC, CHD or DM overall and for overweight and obese individuals who are both at high and low risk of disease, perceived risk estimates are often inaccurate. Primary care doctors should be aware that their patients’ perceived risks may not necessarily correspond to actual risks. Public health education should focus on correcting perceptions of disease risk, and further research is needed to determine the most appropriate education and whether correct perceptions lead to improved behavioral and health outcomes.

Funding

This work was supported by 5R18HS018644 from the Agency for Healthcare Research and Quality and U54CA163307 from the National Cancer Institute (NCI) Population-based Research Optimizing Screening through Personalized Regimens (PROSPR) initiative.

Competing interests

The authors declare no competing interest.

Author details

Phyllis Brawarsky¹
E-mail: pbrawarsky@bwh.partners.edu
Katyuska Eibensteiner¹
E-mail: keibensteiner@partners.org
Elissa V. Klinger¹
E-mail: eklinger@partners.org
Heather J. Baer^{1,2,3}
E-mail: hbaer@bwh.harvard.edu
George Getty¹
E-mail: ggetty1@partners.org
E. John Orav¹
E-mail: eorav@bwh.harvard.edu
Graham Colditz⁴
E-mail: colditz@wudosis.wust1.edu

Jennifer S. Haas^{1,2,3}

E-mail: jhaas@bwh.harvard.edu

¹ Division of General Medicine and Primary Care, Brigham and Women’s Hospital, 1620 Tremont Street, Boston, MA 02120, USA.

² Department of Medicine, Harvard Medical School, USA.

³ Departments of Epidemiology and Social and Behavioral Sciences, Harvard TH Chan School of Public Health, USA.

⁴ Division of Public Health Sciences, Washington University School of Medicine, USA.

Citation information

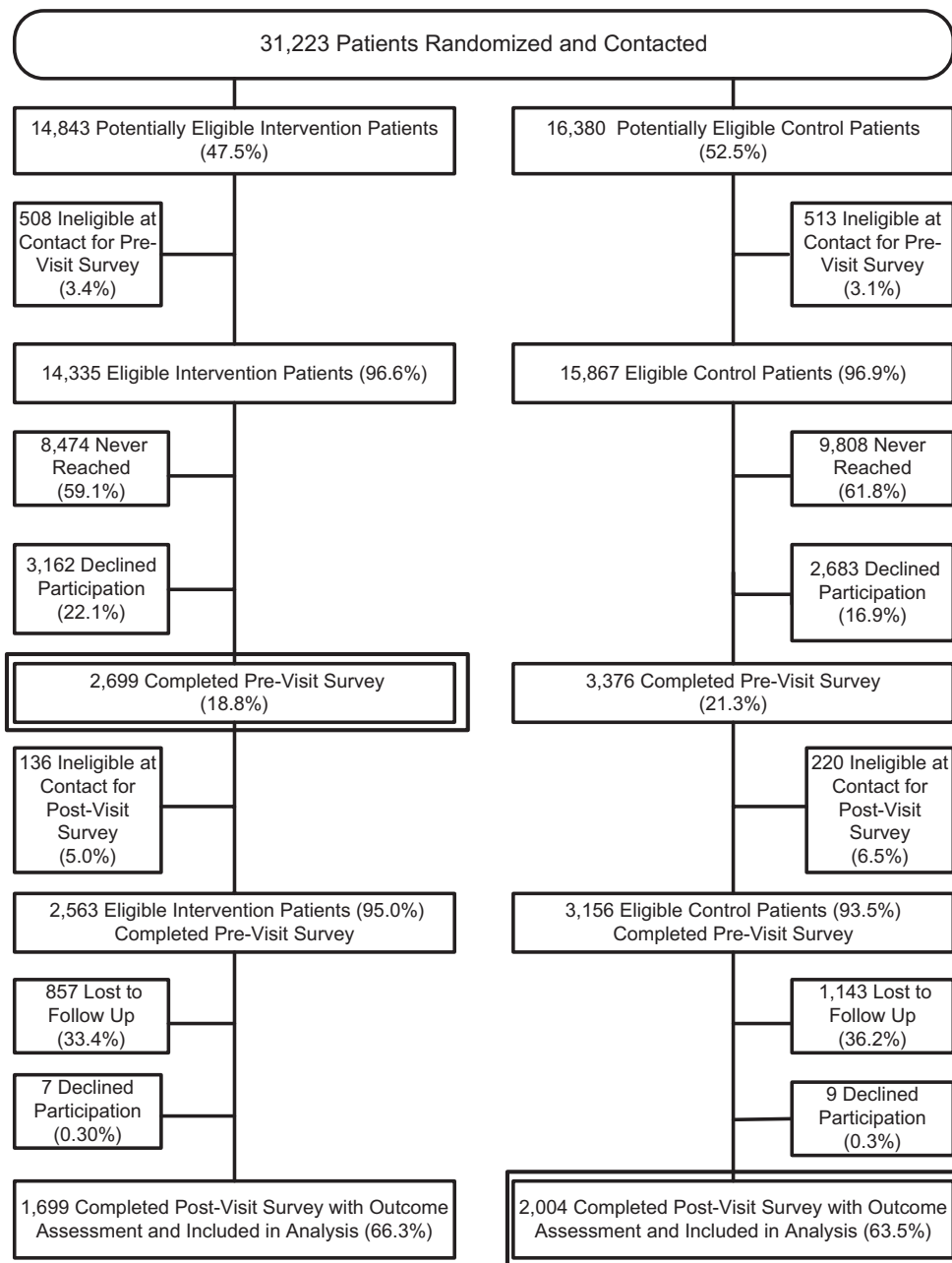
Cite this article as: Accuracy of self-perceived risk for common conditions, Phyllis Brawarsky, Katyuska Eibensteiner, Elissa V. Klinger, Heather J. Baer, George Getty, E. John Orav, Graham Colditz & Jennifer S. Haas, *Cogent Medicine* (2018), 5: 1463894.

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Appendix A. Consort diagram





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