Psychosocial, attitudinal, and demographic correlates of cancer-related germline genetic testing in the 2017 Health Information National Trends Survey

Megan C. Roberts¹ · Erin Turbitt² · William M. P. Klein^{1,2}

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Abstract

The study objective was to examine bivariate and multivariate associations among worry, perceptions, attitudes, sociodemographics, and uptake of cancer-related germline genetic testing. We used data from the Health Information National Trends Survey (cycle 5.1), administered (January–May 2017) to a nationally representative sample of non-institutionalized adults ($n = 3285$). Those who had “heard about genetic tests that determine how a disease can be treated” had a higher likelihood of Lynch syndrome and *BRCA1/2* testing ($aRR = 2.57, p < 0.01$; $aRR = 3.23, p < 0.04$). Attitudinal and psychosocial variables were not associated with uptake. Future research should explore ways to educate the public about the potential use of genetics in treatment decision-making.

Keywords Genetic testing · *BRCA1/2* · Lynch syndrome · Uptake · Cancer · Psychosocial factors · Health beliefs

Introduction

Since the completion of the Human Genome Project, the rate of genomic discovery has been exponential, and increasingly, genomics has the potential to benefit patient health (Khouri et al. 2007). Evidence-based practices in genomics can guide clinical care by determining disease risk, treatment after diagnosis, drug selection, and the likelihood of passing an inherited disease to children (Manolio et al. 2013). Knowledge about genetics (Quinlivan et al. 2014) and psychosocial and attitudinal factors among patients and the public are important considerations in the translation of genomic medicine into clinical care and public health practice, as they are related to intentions and uptake of testing (Wade et al. 2012).

The Multiplex Genetic Testing Model (Wade et al. 2012) combines constructs from several health behavior theories, including the *Theory of Planned Behavior* (Ajzen 1991),

Protection Motivation Theory (Rogers and Prentice-Dunn 1997), and the *Health Belief Model* (Champion and Skinner 2002). The model posits that these constructs, including worry, perceptions, attitudes, and sociodemographic characteristics (i.e., race, education, gender, marital status, age), are associated with intentions to undergo multiplex genetic testing and uptake of testing (which included testing for 15 variants that contribute to disease risk including colorectal cancer) (Wade et al. 2012). Indeed, cancer beliefs, cancer worry, and higher risk perceptions have been associated with a higher odds of cancer prevention behaviors as well as cancer screening (Idowu et al. 2016). Higher perceived cancer risk has been associated with increased odds of being aware of genetic testing (Agurs-Collins et al. 2015) and a higher likelihood of participating in genetic risk assessment for hereditary breast and ovarian cancer (Sherman et al. 2014). On the other hand, some psychosocial characteristics such as cancer information avoidance have been related to a lower likelihood of cancer screening (Emanuel et al. 2015). While the Multiplex Genetic Testing Model was originally conceptualized in the context of multiplex genetic testing, many of the constructs have been shown to be relevant for other types of testing such as cancer-related germline genetic testing (Thompson et al. 2002; Peters et al. 2005; Hann et al. 2017).

Hereditary breast and ovarian cancer (*BRCA1/2* mutations) and Lynch syndromes (LS) are the two most common

✉ Megan C. Roberts
megan.roberts@nih.gov

¹ National Cancer Institute, 9609 Medical Center Drive,
Rockville, MD 20850, USA

² National Human Genome Research Institute, 31 Center Drive,
Bethesda, MD 20892-2152, USA

hereditary cancer disorders. Individuals with *BRCA1/2* mutations and Lynch syndrome-related mutations are at increased risk of several cancers relative to the average population (Petrucelli et al. 2016; Moller et al. 2017); however, the literature suggests that approximately 50% or fewer undergo genetic testing (Sharaf et al. 2013; Childers et al. 2017). This is unfortunate as the cancer burden experienced by this high-risk population can be reduced via their identification through genetic testing and subsequent follow-up with enhanced cancer screening and surgical prevention (Evaluation of Genomic Applications in and Prevention Working 2009; Moyer and Force 2014). Conversely, cancer-related germline genetic testing among individuals who are not at high risk for hereditary cancer disorders may underlie potential harms associated with overuse (e.g., misinterpretation of results) (Roberts and Dusetzina 2017). Thus, understanding how psychosocial and attitudinal constructs from an adapted Multiplex Genetic Testing model are associated with genetic test uptake could provide targets for improving appropriate uptake of genetic testing.

To our knowledge, no nationally representative studies have examined how constructs from the Multiplex Genetic Testing Model are associated with uptake of genetic testing for *BRCA1/2* or Lynch syndrome. Accordingly, this study builds from previous work examining bivariate and multivariate demographic correlates of genetic test uptake in the same sample (Krakow et al. 2018) by examining the associations among worry, perceptions, attitudes, and sociodemographic characteristics and uptake of *BRCA1/2* and Lynch syndrome testing.

Methods

We used data from the Health Information National Trends Survey (HINTS 5, cycle 1), administered by mail (January–May 2017) to a nationally representative sample of non-institutionalized adults (i.e., individuals who are not in military, jail, permanent nursing homes, or other institutions) in

the USA ($n = 3285$) (Westat 2017). HINTS collects annual information about the use of cancer-related germline testing for *BRCA1/2* and Lynch syndrome by the public (hereafter referred to as “cancer-related germline genetic testing”). We report nationally weighted descriptive statistics for the following survey items on awareness about genetic testing and the use of cancer-related germline genetic testing:

- (1) “Doctors use DNA tests to analyze someone’s DNA for health reasons. Have you heard or read about this type of genetic test?”
- (2) Among those who reported hearing about genetic tests ($n = 1878$), “Which of the following uses of a genetic test have you heard of? (a) Determining risk or likelihood of getting a particular disease (b) Determining how a disease should be treated after diagnosis (c) Determining which drug(s) may or may not work for an individual (d) Determining the likelihood of passing an inherited disease to your children,”
- (3) Have you ever been tested for *BRCA1/2* mutations; Have you ever been tested for Lynch syndrome?

Among those who replied “yes” to having heard or read about genetic testing (see survey item 1 above), we examined bivariate differences (weighted chi-square/*t* tests) among those who were tested for *BRCA1/2* and Lynch syndrome compared to those who did not receive testing. We selected independent variables based on the Multiplex Genetic Testing Model proposed by Wade et al. (2012), and examined bivariate differences in race, age, sex, education, marital status, risk perception, cancer beliefs, cancer information avoidance (i.e., *I’d rather not know my chance of getting cancer*), and worry (see Fig. 1). We further adapted this model by adding three additional variables: (1) awareness about genetic testing (see survey item 2 above); and (2) personal and (3) family cancer history, as clinical guidelines recommend individuals for cancer-related germline genetic testing with certain personal and family cancer histories (Daly et al. 2017; Gupta et al. 2017) (see Fig. 1). Independent variables with $p < 0.10$ were included in a multivariable modified Poisson regression model to

Fig. 1 Guiding conceptual model adapted from the Wade et al. Multiplex Genetic Testing Model to the context of genetic testing for Lynch syndrome and *BRCA1/2* testing (Wade, Shiloh et al. 2012)

examine their association with *BRCA1/2* and Lynch syndrome testing separately. Adjusted risk ratios were reported (STATASE14, STATA Corp, College Station, TX).

Results

Respondents included in this study were primarily white (81%), on average 48 years old, and had some college or professional education or higher (76%). About half the sample was male (47%) and married (57%). (Table 1) About 57% of respondents were aware of genetic testing (57.1%, 95%CI = 0.55, 0.60). Overall, among those who had heard of genetic tests, 40% of respondents knew that genetic tests could be used to determine disease treatment or drug choice (40.7%, 95%CI = 0.37, 0.44 and 43.3%, 95%CI = 0.39, 0.47, respectively). Within this nationally representative sample, 5% reported *BRCA1/2* testing and less than 3% reported testing for Lynch syndrome genetic testing (see also Krakow et al. 2018) (Table 1).

Being aware that genetic testing can guide treatment decisions was related to uptake of *BRCA1/2* and Lynch syndrome testing in both descriptive (Table 1) and multivariable models (adjusted risk ratio (aRR) = 2.57, $p < 0.01$; aRR = 3.23, $p < 0.04$, respectively) (Table 2). For Lynch syndrome, a higher proportion of those who were tested had a family history of cancer than those who were untested; however, this association did not hold in our multivariable model.

Of interest, we did not find associations between the psychosocial or attitudinal variables and receipt of cancer-related germline genetic testing. Individuals who were cancer information avoidant were equally likely to receive versus not receive cancer-related germline genetic testing for cancer predisposition genes. Further, risk perceptions and cancer beliefs were not associated with uptake of testing.

Discussion

Within this nationally representative sample, 5% reported *BRCA1/2* testing and less than 3% reported testing for Lynch syndrome genetic testing. We found that worry, perceptions, and attitudes as well as sociodemographic characteristics were not associated with uptake of cancer-related germline genetic testing. This was surprising as previous studies have indicated that these constructs are important to engagement with genetic testing (Wade et al. 2012; Sherman et al. 2014; Agurs-Collins et al. 2015). The finding may be partially related to differences in our study population, a nationally representative sample. Unlike prior studies, which typically involve convenience samples, our findings may more accurately represent psychosocial and attitudinal correlates of testing across the American public. Further, we were unable to examine psychosocial and attitudinal constructs directly related to cancer-related

germline genetic testing; instead, we examined the association between constructs related to beliefs, attitudes, and perceptions about cancer with cancer-related germline genetic testing uptake. Attitudes about genetic testing, specifically, may be more directly associated with test uptake, and should be examined in future research to understand how a broader range of psychosocial and attitudinal constructs are associated with genetic testing uptake.

We also found that those who are cancer information avoidant were equally as likely to have reported having cancer-related germline genetic testing as those who were not avoidant. This suggests that among a nationally representative sample, testing decisions may be misaligned with preferences to know about cancer risks. More specifically, our finding suggests that those who had cancer-related germline genetic testing and were cancer information avoidant may have made less informed choices, as their attitudes were in opposition to their testing behavior (Marteau et al. 2001). We were surprised that cancer information avoidant individuals had undergone genetic testing for cancer risk as prior studies demonstrate that those who are information avoidant are less likely to engage with cancer screening (Emanuel et al. 2015). Differences in findings may be due to the unique nature of cancer-related germline genetic testing, which, unlike cancer screening, provides not only one's own cancer risk information but also potential risk information for relatives.

In a post-hoc analysis, we found that among those who were cancer avoidant, those who engaged in *BRCA1/2* and Lynch syndrome testing were more likely to be aware that genetic testing can determine the likelihood of passing an inherited disease to one's children than those who were not tested (*BRCA1/2* testing: 84.1% untested vs 98.2% tested $p = 0.001$; Lynch syndrome testing: 84.4% untested vs. 98.0% tested $p = 0.02$). This suggests that other information preferences (i.e., knowing the likelihood of passing disease to children) may take priority over avoiding one's own cancer risk information, which aligns with current literature demonstrating that knowing the likelihood of passing a disease to children is a facilitator for genetic testing in families with known genetic mutations (Rajpal et al. 2017; Roberts et al. 2018). Taken together, these findings may have implications for informed decision-making moving forward, and future studies should examine this more explicitly.

Across our sample, over 85% were aware that genetics both determines the risk of getting a particular disease and determines the likelihood of passing on an inherited disease to children. However, these awareness questions were not associated with cancer-related germline genetic testing status. In contrast, we found that only 40% were aware that genetic testing can be used to guide treatment. Indeed, another study (among participants undergoing whole exome sequencing) reported that participants had a better understanding of heredity concepts compared to knowledge that genome sequencing

Table 1 Weighted bivariate associations between worry, perceptions, attitudes, knowledge, and sociodemographic characteristics

Variable	Overall (%)		Lynch Syndrome (%)		BRCA1/2 (%)	
	Not Tested N = 1840 Wgt. N = 138,783,727	Tested for Lynch syndrome N = 32 Wgt. N = 3,596,434	Not Tested N = 1808 Wgt. N = 135,187,293	Tested for Lynch syndrome N = 32 Wgt. N = 3,596,434	Not Tested N = 1738 Wgt. N = 131,855,442	Tested for BRCA1/2 N = 102 Wgt. N = 6,928,285
Have you heard of genetics						
Determining risk or likelihood of getting a particular disease	87.7	87.6	91.3	91.3	0.48 87.4	93.0 0.13
Determining how a disease should be treated after diagnosis	40.8	39.9	72.2	72.2	0.01 39.4	65.0 <0.01
Determining which drug(s) may or may not work for an individual	43.2	42.7	51.0	51.0	0.56 42.6	54.2 0.20
Determining the likelihood of passing an inherited disease to your children	86.5	86.1	94.3	94.3	0.15 86.1	93.1 0.08
Race						
White	81.4	81.7	66.7	66.7	81.5	79.1 0.79
Black	9.4	9.1	22.8	22.8	9.2	13.7
AIAN	0.6	0.6	0.0	0.0	0.6	0.0
Multiracial	3.8	3.9	2.3	2.3	3.8	4.5
Asian	4.6	4.5	8.2	8.2	4.7	2.7
PI	0.3	0.3	0.0	0.0	0.3	0.0
Age	47.6 (16.7)	47.9 (16.6)	37.7 (15.1)	37.7 (15.1)	0.10 47.8 (16.4)	43.6 (20.5) 0.26
Male (vs. female)	46.9	46.8	50.9	50.9	0.79 47.6	34.3 0.14
Education						
Less than high school	6.3	6.2	9.7	9.7	6.5	2.2 0.40
High school or 12	17.8	17.7	22.8	22.8	18.0	13.3
Some college or professional	33.6	33.9	24.5	24.5	33.8	29.9
College	24.9	24.7	29.3	29.3	24.2	36.6
Post college	17.4	17.5	13.6	13.6	17.4	17.9
Married/living as married (vs. unmarried)	56.8	56.7	57.9	57.9	0.95 56.5	61.5 0.64
How likely are you to get cancer in your lifetime? (1 very unlikely, 5 very likely)	3.3 (0.9)	3.3 (0.9)	3.6 (0.5)	3.6 (0.5)	0.14 3.2 (0.9)	3.5 (0.9) 0.06
Cancer beliefs/attitudes (1 strongly agree, 4 strongly disagree)						
It seems like everything causes cancer	2.3 (0.9)	2.3 (0.9)	2.1 (0.7)	2.1 (0.7)	0.54 2.3 (0.9)	2.2 (0.8) 0.69
There's not much you can do to lower your chances of getting cancer	3.1 (0.8)	3.1 (0.8)	3.2 (0.7)	3.2 (0.7)	0.77 3.1 (0.8)	3.2 (1.0) 0.62
There are so many recommendations about preventing cancer it is hard to know which to follow	2.1 (0.8)	2.1 (0.8)	2.2 (0.5)	2.2 (0.5)	0.81 2.1 (0.8)	2.1 (0.8) 0.95
In adults, cancer is more common than heart disease	2.7 (0.8)	2.7 (0.8)	2.3 (0.6)	2.3 (0.6)	0.13 2.7 (0.8)	2.5 (0.9) 0.19
When I think about cancer, I automatically think about death	2.3 (0.9)	2.3 (1.0)	2.5 (0.6)	2.5 (0.6)	0.40 2.3 (1.0)	2.3 (0.9) 0.91
Cancer Information Avoidance: I'd rather not know my chance of getting cancer (1 strongly agree, 4 strongly disagree)	2.9 (1.0)	2.9 (1.0)	2.8 (0.8)	2.8 (0.8)	0.85 2.9 (1.0)	3.1 (1.1) 0.32
How worried are you about getting cancer? (1 not at all, 5 extremely)	2.6 (1.0)	2.6 (1.1)	3.0 (0.7)	3.0 (0.7)	0.19 2.6 (1.0)	2.9 (1.0) 0.09

Table 1 (continued)

Variable	Overall (%)		Lynch Syndrome (%)		BRCA1/2 (%)	
		<i>p</i>	Not Tested	Tested for Lynch syndrome	Not Tested	Tested for BRCA1/2
	<i>N</i> = 1840 Wgt. <i>N</i> = 138,783,727		<i>N</i> = 1808 Wgt. <i>N</i> = 135,187,293	<i>N</i> = 32 Wgt. <i>N</i> = 3,596,434	<i>N</i> = 1738 Wgt. <i>N</i> = 131,855,442	<i>N</i> = 102 Wgt. <i>N</i> = 6,928,285
Personal history of cancer	9.1	9.1	9.1	10.6	8.9	13.2
Family history of cancer						
Yes	72.0	71.5	71.5	90.8	71.4	83.6
No	23.1	23.6	23.6	7.3	23.6	14.8
Unsure	4.9	4.9	4.9	1.9	5.0	1.6

Table 2 Multivariable correlates of uptake of Lynch syndrome and BRCA1/2 testing

	Adjust risk ratio	95% CI	<i>p</i> value
Lynch syndrome testing ⁺			
Heard of genetics determining how a disease should be treated after diagnosis? (vs. did not hear)	3.23	1.07, 9.81	0.04
Age	0.97	0.94, 1.00	0.06
Family history of cancer (vs. none)	0.25	0.06, 1.07	0.06
BRCA1/2 testing ⁺⁺			
Heard of genetics determining how a disease should be treated after diagnosis. (v. did not hear)	2.57	1.29, 5.14	0.009
Heard of genetics determining the likelihood of passing an inherited disease to children. (v. did not hear)	1.71	0.67, 4.37	0.25
Perceived cancer risk (1 low–5 high)	1.36	0.85, 2.17	0.20
Cancer worry			
(1 not at all—extremely)	1.23	0.84, 1.82	0.28

⁺ *N* = 1173, Weighted *N* = 129,486,758⁺⁺ *N* = 1172, Weighted *N* = 129,288,463

could identify variants related to treatment (Kaphingst et al. 2012). It is possible that awareness about the role of genetics in disease treatment represents knowledge about the clinical utility of a test (Grosse and Khoury 2006), beyond simply providing information about disease risk and inheritance. Moreover, we found that awareness about the role of genetics in disease treatment was associated with a higher likelihood of receiving cancer-related germline genetic testing for *BRCA1/2* and Lynch syndrome. Educational efforts around the clinical utility of genetic testing will be important as we seek to incorporate genomic medicine into care more routinely for multiple facets of disease prevention and treatment.

Although this study leverages a national, population-based dataset, it has several limitations. First, although we can examine uptake of cancer-related germline genetic testing, we are unable to determine whether this uptake was aligned with clinical guidelines for testing. In particular, our measure of family history was general and did not provide the specificity needed to determine whether an individual would be eligible for cancer-related germline genetic testing based on family history and likely explains the lack of association between family history and test uptake. Further, measures are self-reported which may limit reliability of measures such as genetic test uptake. Future studies should examine the roles of genetic testing awareness, knowledge, and preferences among those who are eligible for genetic testing. Second, while we were able to look at the association of cancer beliefs on genetic testing uptake for *BRCA1/2* and Lynch syndrome, data specific to beliefs about genetics were not available. Third, because these data are cross-sectional, we cannot assume causality or temporality. The association between awareness about genetic testing for disease treatment may represent knowledge that precedes testing or is acquired during the testing process. Future prospective research can examine this explicitly. Fourth, our awareness items about genetic testing measure awareness and not necessarily deeper understanding, thus we cannot study the extent to which respondents conflate different uses of genetic testing. Finally, while we used measures from the published literature (Agurs-Collins et al. 2015), some constructs (e.g., cancer worry) were measured with single items and may not fully capture their dimensionality. It is possible that these limitations contributed to differences seen in the literature regarding the association between psychosocial and attitudinal beliefs and genetic testing.

Conclusions

These findings provide nationally representative data about uptake of genetic testing for *BRCA1/2* and Lynch syndrome in the USA. Overall, educational efforts should target informing the public about the role of genetics for guiding treatment decisions, as this was related to uptake of cancer-

related germline genetic testing and demonstrates a potential gap in the public's awareness about genetic testing more broadly. Additional work is warranted to ensure that uptake of cancer-related germline testing is aligned with preferences for information seeking. Finally, to better understand psychosocial and attitudinal factors associated with testing, other constructs, such as time orientation and trust in medical practice, should be explored to more fully understand uptake of genetic testing for cancer hereditary syndromes nationally.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human or animal subjects performed by any of the authors.

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References

- Agurs-Collins T, Ferrer R, Ottenbacher A, Waters EA, O'Connell ME, Hamilton JG (2015) Public awareness of direct-to-consumer genetic tests: findings from the 2013 U.S. Health Information National Trends Survey. *J Cancer Educ* 30(4):799–807
- Ajzen I (1991) The theory of planned behavior. *Organ Behav Hum Decis Process* 50:179–211
- Champion VL, Skinner CG (2008) The health belief model. In: Glanz K, Rimer BK, Viswanath K (eds) *Health behavior and health education: theory, research, and practice*. Jossey-Bass, San Francisco, pp 45–62
- Childers CP, Childers KK, Maggard-Gibbons M, Macinko J (2017) National estimates of genetic testing in women with a history of breast or ovarian cancer. *J Clin Oncol* 35(34):3800–3806
- Daly MB, Pilarski R, Berry M, Buys SS, Farmer M, Friedman S, Garber JE, Kauff ND, Khan S, Klein C, Kohlmann W, Kurian A, Litton JK, Madlensky L, Merajver SD, Offit K, Pal T, Reiser G, Shannon KM, Swisher E, Vinayak S, Voian NC, Weitzel JN, Wick MJ, Wiesner GL, Dwyer M, Darlow S (2017) NCCN guidelines insights: genetic/familial high-risk assessment: breast and ovarian, version 2.2017. *J Natl Compr Cancer Netw* 15(1):9–20
- Emanuel AS, Kiviniemi MT, Howell JL, Hay JL, Waters EA, Orom H, Shepperd JA (2015) Avoiding cancer risk information. *Soc Sci Med* 147:113–120
- Evaluation of Genomic Applications in Practice and Prevention Working Group (2009) Recommendations from the EGAPP Working Group: genetic testing strategies in newly diagnosed individuals with colorectal cancer aimed at reducing morbidity and mortality from Lynch syndrome in relatives. *Genet Med* 11(1):35–41

- Grosse SD, Khoury MJ (2006) What is the clinical utility of genetic testing? *Genet Med* 8(7):448–450
- Gupta S, Provenzale D, Regenbogen SE, Hampel H, Slavin TP Jr, Hall MJ, Llor X, Chung DC, Ahnen DJ, Bray T, Cooper G, Early DS, Ford JM, Giardiello FM, Grady W, Halverson AL, Hamilton SR, Klapman JB, Larson DW, Lazenby AJ, Lynch PM, Markowitz AJ, Mayer RJ, Ness RM, Samadder NJ, Shike M, Sugandha S, Weiss JM, Dwyer MA, Ogba N (2017) NCCN guidelines insights: genetic/familial high-risk assessment: colorectal, version 3.2017. *J Natl Compr Cancer Netw* 15(12):1465–1475
- Hann KEJ, Freeman M, Fraser L, Waller J, Sanderson SC, Rahman B, Side L, Gessler S, Lanceley A, team P s (2017) Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. *BMC Public Health* 17(1):503
- Idowu KA, Adenuga B, Otubu O, Narasimhan K, Kamara F, Hunter-Richardson F, Larbi D, Sherif ZA, Laiyemo AO (2016) Place of birth, cancer beliefs and being current with colon cancer screening among US adults. *Ann Gastroenterol* 29(3):336–340
- Kaphingst KA, Facio FM, Cheng MR, Brooks S, Eidem H, Linn A, Biesecker BB, Biesecker LG (2012) Effects of informed consent for individual genome sequencing on relevant knowledge. *Clin Genet* 82(5):408–415
- Khoury MJ, Gwinn M, Yoon PW, Dowling N, Moore CA, Bradley L (2007) The continuum of translation research in genomic medicine: how can we accelerate the appropriate integration of human genome discoveries into health care and disease prevention? *Genet Med* 9(10):665–674
- Krakow M, Ratcliff CL, Hesse BW, Greenberg-Worisek AJ (2018) Assessing genetic literacy awareness and knowledge gaps in the US population: results from the Health Information National Trends Survey. *Public Health Genomics*:1–6
- Manolio TA, Chisholm RL, Ozenberger B, Roden DM, Williams MS, Wilson R, Bick D, Bottinger EP, Brilliant MH, Eng C, Frazer KA, Korf B, Ledbetter DH, Lupski JR, Marsh C, Mrazek D, Murray MF, O'Donnell PH, Rader DJ, Relling MV, Shuldiner AR, Valle D, Weinshilboum R, Green ED, Ginsburg GS (2013) Implementing genomic medicine in the clinic: the future is here. *Genet Med* 15(4):258–267
- Marteau TM, Dormandy E, Michie S (2001) A measure of informed choice. *Health Expect* 4(2):99–108
- Moller P, Seppala T, Bernstein I, Holinski-Feder E, Sala P, Evans DG, Lindblom A, Macrae F, Blanco I, Sijmons R, Jeffries J, Vasen H, Burn J, Nakken S, Hovig E, Rodland EA, Tharmaratnam K, de Vos Tot Nederveen Cappel WH, Hill J, Wijnen J, Green K, Laloo F, Sunde L, Mints M, Bertario L, Pineda M, Navarro M, Morak M, Renkonen-Sinisalo L, Frayling IM, Plazzer JP, Pylvanainen K, Sampson JR, Capella G, Mecklin JP, Moslein G, Mallorca G (2017) Cancer incidence and survival in Lynch syndrome patients receiving colonoscopic and gynaecological surveillance: first report from the prospective Lynch syndrome database. *Gut* 66(3):464–472
- Peters N, Domchek SM, Rose A, Polis R, Stopfer J, Armstrong K (2005) Knowledge, attitudes, and utilization of BRCA1/2 testing among women with early-onset breast cancer. *Genet Test* 9(1):48–53
- Petrucelli N, D. M., Pal T. (2016) "BRCA1- and BRCA2-associated hereditary breast and ovarian cancer." *GeneReviews*, 2018, from <https://www.ncbi.nlm.nih.gov/books/NBK1247/>. Accessed 13 Feb 2019
- Quinlivan JA, Battikhi Z, Petersen RW (2014) What factors impact upon a woman's decision to undertake genetic cancer testing? *Front Oncol* 3:325
- Rajpal N, Munoz J, Peshkin BN, Graves KD (2017) Insights into BRCA1/2 genetic counseling from ethnically diverse Latina breast cancer survivors. *J Genet Couns* 26(6):1221–1237
- Roberts MC, Dusetzina SB (2017) The effect of a celebrity health disclosure on demand for health care: trends in BRCA testing and subsequent health services use. *J Community Genet* 8(2):141–146
- Roberts MC, Dotson WD, DeVore CS, Bednar EM, Bowen DJ, Ganiats TG, Green RF, Hurst GM, Philp AR, Ricker CN, Sturm AC, Trepanier AM, Williams JL, Zierhut HA, Wilemon KA, Hampel H (2018) Delivery of cascade screening for hereditary conditions: a scoping review of the literature. *Health Aff (Millwood)* 37(5):801–808
- Rogers RW, Prentice-Dunn S (1997) Protection motivation theory. In: Gochman DS (ed) *Handbook of health behavior research 1: personal and social determinants*. New York, Plenum Press, pp 113–132
- Sharaf RN, Myer P, Stave CD, Diamond LC, Ladabaum U (2013) Uptake of genetic testing by relatives of lynch syndrome probands: a systematic review. *Clin Gastroenterol Hepatol* 11(9):1093–1100
- Sherman KA, Miller SM, Shaw LK, Cavanagh K, Sheinfeld Gorin S (2014) Psychosocial approaches to participation in BRCA1/2 genetic risk assessment among African American women: a systematic review. *J Community Genet* 5(2):89–98
- Thompson HS, Valdimarsdottir HB, Duteau-Buck C, Guevarra J, Bovbjerg DH, Richmond-Avellaneda C, Amarel D, Godfrey D, Brown K, Offit K (2002) Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. *Cancer Epidemiol Biomark Prev* 11(12):1579–1585
- United States Preventive Services Task Force (2014) Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: U.S. preventive services task force recommendation statement. *Ann Intern Med* 160(4):271–281
- Wade CH, Shiloh S, Woolford SW, Roberts JS, Alford SH, Marteau TM, Biesecker BB (2012) Modelling decisions to undergo genetic testing for susceptibility to common health conditions: an ancillary study of the multiplex initiative. *Psychol Health* 27(4):430–444
- Westat (2017) Health Information National Trends Survey 5 (HINTS 5) cycle 1 methodology report. Health Information National Trends Survey. Westat