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Exploring the Interface of Genetics, Genomics, and Older Adults

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EXPLORING THE INTERFACE OF GENETICS, GENOMICS, AND OLDER ADULTS

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by
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ABSTRACT

This dissertation addresses the interface of genetics, genomics, and older adults through a collection of three manuscripts that examine genetic and genomic testing and decision-making across age groups. The dissertation offers evaluations of a new lens for decision-making in genetics and genomics, a contextualization of the differences and similarities of perceptions and beliefs that exist among age groups engaging in direct-to-consumer personal genetic testing (DTC PGT), an identification of two factors that influence the decision to engage in DTC PGT, and an expansion of the current applications of Protection Motivation Theory to include disclosure, finance, and advance directive-management behaviors related to DTC PGT results.

Together these three manuscripts support and expand on previous understandings about older adults and decision-making in genetics and genomics. The dissertation findings identify many unique qualities of the 60+year old age group while also finding similarities that span age groups. These findings support the need for further examination of both age-group differences and the phenomenon of genetic or genomic decision-making. The differences and similarities among age groups will provide initial findings on which future work in decision-making and decision-support can be built. The dissertation's focus on context as a key component of decision-making is both timely and forward looking. The need to create unique and informed decision-support interventions is growing as the personalized medicine movement begins to bring in more genetic information. Consumer-driven healthcare demands consumer-sensitive approaches. The use of behavioral economics and the Protection Motivation Theory as guides will help

healthcare professionals to address the age-group differences and the individual contexts that shape the genetic decision-making process.

Keywords: Behavioral Economics, Genetics, Older Adults, Protection Motivation Theory.

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DEDICATION

I dedicate this dissertation to my mother, Debbie Denise Dobson Moore, and my late father, Robert Coffer Moore, without whom I may not have ever taken the chances that have led me to the PhD.

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CHAPTER ONE:

INTRODUCTION

Exploring the Interface of Genetics, Genomics, and Older Adults

In the post-Human Genome Project era, as the cost of whole genome sequencing is reaching the $1,000 mark, the need for complementary ethical, legal, social implications (ELSI) research has increased (Green, Guyer, & National Human Genome Research Institute, 2011). The intersection of technology, health care, and society is one that is characterized by constant change; the possibility and promise of new approaches to diagnosis, health promotion, and treatment and prevention of disease make genomics an important part of improving healthcare. Ethical, legal, and social implications research is imperative in supporting translational genomic science (Green et al., 2011). The applications of genetic knowledge to clinical care have changed dramatically over the past 25 years and are anticipated to change even more as genetic technology, knowledge, and access increase in the future (Catenacci et al., 2015; Green et al., 2011; Sobel & Cowan, 2000a). These changes in applications are happening, not only because of the increase in the relative availability of testing, but also because of the growing understanding that genetic diseases are family diseases (Forrest et al., 2007; Sorenson, Jennings-Grant, & Newman, 2003).

Published studies addressing families and genetics cover a range of topics including risk perceptions, disclosure of results, and effects of results on family (Forrest et al., 2007; Lautenbach, Christensen, Sparks, & Green, 2013; Sorenson et al., 2003). As an effect of the growing number of older adults who are living longer and engaging with

newer healthcare technologies, the family unit, as it has been characterized in the past, is in flux (Bookman & Kimbrel, 2011; Seals, Justice, & LaRoca, 2015). It is important to have a general understanding of the familial and generational impacts that genetic testing decisions can have through the avoidance or revelation of new genetic information about a person and his family (Frazier & Ostwald, 2002).

The understanding of older adults' genetic knowledge, genetic perceptions, and beliefs is limited. The few studies that address aspects of older adults in relation to genetics tend to highlight low levels of genetic literacy and knowledge among older adults and often associate it with lack of exposure to the knowledge in their education (Ashida et al., 2011; Carere et al., 2015; Frazier, Calvin, Mudd, & Cohen, 2006; Morren, Riken, Baanders, & Bensing, 2007; Ostergren et al., 2015; Skirton, Frazier, Calvin, & Cohen, 2005). Other findings regarding older adults and genetics include an increased likelihood to defer to clinical expertise of a health care provider rather than to take responsibility for the issues related to medical genetic decisions (Frazier et al., 2006) and an altruistic and generative quality when considering the possibility of genetic testing (Skirton et al., 2005). While genetic knowledge may be foundational to many other tasks related to genetic testing, there are many other factors and influences that must be considered with the complex undertaking of making decisions regarding genetic information.

This dissertation is intended to increase current understanding of the perceptions, beliefs, attitudes and behaviors of older adults regarding genetic and genomic testing and

decision-making, as well as, the usefulness and application of genetic and genomic information.

Problem Statement

While it long has been understood that any genetic or genomic testing can have implications for more than one person (*e.g.* the information gained from BRCA testing in an older adult female with breast cancer, which may affect her three daughters), there is limited understanding of how genetic decision-making among older adults is undertaken, and how different parties may be engaged in the decision-making processes. Recent academic and practice-based discussions about incidental findings demonstrate the need for ethical and policy-focused studies of advancing medical technologies. The inclusion of new technologies in healthcare requires finding a delicate balance between doing too little, too late and too much, too early.

As a result of the progression of genomic science and the increasing length of life of older adults, it is imperative that research focuses on the implications that genomic-related decision-making and testing have on older adults and their families. Research must address the needs of older adult patients and their adult children (families) as they engage in making genetic testing-related decisions (Sobel & Cowan, 2000a). In order to begin to better understand the implications of genetic information on older adult patients and their families, further descriptive study is required.

The knowledge made possible through early descriptive studies is integral to the development of future tools and identification of best practices. Much work in genomics continues to focus on the younger populations (*e.g.* incidental findings disclosure, adult-

onset disease risk disclosure during childhood, parental consent), but very little attention has been paid to older adult populations and the potential effects that genomics may have on their lives and consequently the lives of their family members. With the rapid growth of the older adult population and increased involvement of family in the care of older adults, discussions regarding genomics have the potential to affect the older adult-family relationship in ways that are unforeseen in younger populations.

Statement of Significance

This dissertation will provide important knowledge about older adult patients and their perspectives about genomics and genetics as compared with younger age groups. The areas of exploration that are key to this study include: the framing of genomic and genetic decision-making; the examination of age group differences in genetic knowledge, perceptions, and beliefs; the exploration of factors that influence decision-making to engage in genetic testing among age groups; and the evaluation of a model for the prediction of direct-to-consumer personal genomic testing (DTC PGT) results utilization behaviors regarding insurance, finances, retirement, advance plans, and disclosure to another person.

Understanding the differences and similarities of decision-making practices among adults of various ages when engaging in personal genetic or genomic testing as well as examining their general perceptions, beliefs, and attitudes about genomics will provide a valuable foundation on which scientists and clinicians can build tools to aid decision-making regarding genetic testing. Additionally, this work has the potential to

lead to future policy and practice changes to ensure that older adults' needs and best interests are met and supported.

Theoretical Framework

The guiding theoretical framework for this dissertation is the Protection Motivation Theory (PMT) as described by Rogers (Maddux & Rogers, 1983; Rogers, 1975, 1983). Originally designed based on the expectancy-value theory with a focus on describing the relationships between fear appeals and health behaviors, the PMT is an intrapersonal-type theory that supposes that individuals' abilities to take in, react to, cope with, and manage threats or negative outcomes are related to their appraisals of the threat and their appraisal of their own coping abilities for dealing with the threat (Floyd, Prentice-Dunn, & Rogers, 2000; Rogers, 1983). Scientific applications of the PMT have varied since its introduction (Floyd et al., 2000). The application of the PMT has included political and environmental concerns in addition to preventative health behaviors, screening behaviors, and disease and injury prevention behaviors.

Protection Motivation Theory Concepts and Relationships

The PMT (Maddux & Rogers, 1983; Rogers, 1983), in its revised version, features three main concepts: threat appraisal, coping appraisal, and protection motivation (Norman, Boer, & Seydel, 2005). The concepts of threat appraisal and coping appraisal are better described in the revision of the theory with expansion of the cognitive mediating processes that are integral in contributing to related intentions and attitudes through the addition of the self-efficacy concept (Floyd et al., 2000; Maddox & Rogers, 1983; Rogers, 1983).

Threat appraisal is best described as the combination of the perceived severity and the perceived vulnerability related to the negative outcome of concern (Rogers, 1983). This negative outcome could be a disease diagnosis, injury, or some other negative experience that can be avoided. Perceived severity is defined in terms of a person's beliefs about the potential bodily harm, interpersonal threats, and intrapersonal threats that would result from the negative outcome. Perceived vulnerability is defined in terms of a person's beliefs that they may experience the negative outcome.

Coping appraisal is described as the combination of perceived self-efficacy and response efficacy related to the negative outcome of concern (Maddox & Rogers, 1983; Rogers, 1983). Response efficacy is defined as a person's beliefs related to the effectiveness of coping responses. Self-efficacy is defined as a person's beliefs about their ability to perform or not perform a behavior (*e.g.*, a recommended response to the negative outcome of concern). The addition of the concept of self-efficacy is the major difference between the initial introduction of the PMT and the revision (Rogers, 1983).

Protection motivation is best described as the intent to adopt a recommended course of action or engage in a protective behavior to limit the likelihood of experiencing the negative outcome (Maddux & Rogers, 1983; Rogers, 1975, 1983). The PMT is based on the assumption that there is a positive linear relationship among severity of the threat, vulnerability to the threat, the ability to cope with the threat, and that engaging in the behavior of concern will decrease risks of the negative outcome (Rogers, 1983). The PMT is key in this dissertation work in that it provides a framework for understanding the

perceptions that older adults have about genomics, and can offer some insight into their individual realities when it comes to managing genomic information.

Purpose

In addition to the theoretical framework, the dissertation is guided by three primary aims and one exploratory aim:

Primary Aim 1*:* Evaluation of behavioral economic concepts as a suitable lens for framing decision-making in genetic and genomic testing.

> ***Research Question 1***: What behavioral economic concepts fit genetic and genomic decision-making situations?

Primary Aim 2*:* Characterize the perceptions and attitudes of older adults regarding genetics, genetic testing, and genetic information.

> ***Research Question 2:*** What are older adults' perceptions regarding genetic testing and genetic information?

Primary Aim 3: Describe the differences in behaviors of genetic testing decision-making and application of genetic information among younger and older age groups.

> ***Research Question 3:*** What are the decision-making processes used by older adults when making decisions regarding genetic testing and genetic information?

Exploratory Aim: Explore the application of the Protection Motivation Theory to genetic information disclosure and utilization behaviors among age groups.

> ***Research Question 4:*** What is the relationship among threat appraisal, coping appraisal, disclosure of genetic results, changes in healthcare insurance and advanced planning behaviors?

This dissertation contextualizes decision-making in genetics and genomics with a specific focus on older adults in comparison to the other age groups. These research questions are answered through three manuscripts: the first manuscript explores genetic and genomic decision-making through the lens of behavioral economics; the second manuscript identifies and explores differences in age groups regarding influences on their decision to seek personal genomic testing; and, the third manuscript explores the use of the PMT to predict disclosure, insurance, retirement, and advanced planning behaviors among Impact of Personal Genomics (PGen) participants following receipt of their personalized genomic testing results.

This dissertation seeks to further the understanding of the nature of differences among age groups regarding genetic knowledge and perceptions, and add an exploration of decision-making, perceived genetic utility, and the influencing factors on the actions taken as a result of receiving genetic testing results (*e.g.* disclosure, adding insurance coverage, *etc*.). The three manuscripts in this dissertation seek to frame the interface of genetics, genomics and older adults. The first manuscript focuses on behavioral economics as a lens for understanding decision-making related to genomics. The second manuscript is based on an analysis of the PGen study data examining commonalities and differences in the PGen study populations' genomic perceptions and knowledge and the influencing factors that are related to choosing to engage in genomic testing as they differ among three age groups (19-39, 40-59, and 60+). The third manuscript explores age and PMT as a suitable model for predicting or explaining behaviors related to the use of genomic information provided in DTC PGT results. These three manuscripts together

advance the understanding of decision-making in genetics and genomics across age groups.

Methodology

The three manuscripts chosen for this dissertation are combined to expand current understanding of the perceptions, beliefs, attitudes and behaviors of older adults regarding genomics, genomic testing, genomic decision-making, and the usefulness and application of genetic information. Exploration and explanation of relationships among beliefs and behaviors within and among age groups with regard to genetic information will increase the knowledge base needed to better guide decision-making in personal and clinical settings.

The first manuscript (Chapter 2) entitled "Behavioral Economics: A Lens for Understanding Genetic and Genomic Decision-Making," is a review article that introduces three behavioral economic concepts and couples them with appropriate genetic and genomic decision-making examples in an evaluation of fit between genetic/genomic decision-making and behavioral economics. In addition to the general overview of behavioral economics and the three featured concepts, the manuscript also identifies next steps in helping to frame genomic decision-making using behavioral economics.

The second manuscript (Chapter 3) entitled "Personal Genomic Testing: Understanding Age-Group Differences in Genetic Knowledge, Perceptions, and Decision-Making" is a data-based article using the PGen Dataset that examines differences among age groups related to perceptions of genomics, genomic knowledge, and influences on decision-making related to engaging in genomic testing. This is

accomplished through two statistical analysis approaches. First is a comparison of the changes between baseline and six-month measures among the three age groups' genetic knowledge, response efficacy, and self-rated competency in genetics. An analysis of variance (ANOVA) was used to conduct these analyses. Also, ANOVA was conducted to evaluate the changes among the three age groups' personal utility measures from the 2-3 week and the six-month follow up surveys.

Second, items evaluating ratings of importance for reasons for testing and amount of consideration given to decision factors were evaluated first by using factor analysis to identify common loading of the factors and then mean scores for each of the two factors were compared among the age groups using ANOVA of means.

The third manuscript (Chapter 4) entitled "Using Age and Protection Motivation Theory to Explore Personal Genomic Testing Result Utilization" is also a data based article from the PGen dataset. This article focuses on evaluating the PMT as a model for examining the use of genomic testing results looking at similarities and differences among age groups. This analysis consists of contingency tables examining age group membership and the following PMT concept measures: perceived utility of genetic information, genetic knowledge, perceived severity of genetic results, perceived vulnerability to genetic illness after getting results, response efficacy after results, and self-efficacy after getting results on whether or not a participant chose to discuss genetic results, make a change in their healthcare insurance, make a change in their retirement, or make a change in their advanced planning behaviors.

The final chapter (Chapter 5) brings the three manuscripts together and attempts to contextualize the dissertation findings. The three manuscripts work to frame the issues related to decision-making in genetic and genomic testing among older adults.

CHAPTER TWO:

BEHAVIORAL ECONOMICS: A NEW LENS FOR UNDERSTANDING GENOMIC DECISION-MAKING

Abstract

Behavioral economics has been identified in previous articles as a key component of understanding genomics. This article seeks to take the next step in examining the insights that can be derived from using them in combination. As genomic science continues to permeate clinical practice, behavioral economics will continue to warrant further exploration and education for nurses and health care providers. Decisions associated with genomics are often not either/or in nature but are complex and may be challenging for all involved. These complexities make behavioral economics an interesting option for framing our understanding of these decisions. This article offers a brief introduction to behavioral economics as a possible tool to help with decision-making related to genomics. Behavioral economic concepts that are specifically examined as new ways to view the complexities of genomic decision-making include relativity, deliberation, and choice architecture. Each concept is discussed with explanatory examples to help understand applicability to clinical practice. The article also explores the next steps and practice implications for further development of the behavioral economic lens.

Keywords: behavioral economics, genomics, decision-making, nursing

Behavioral Economics: A New Lens for Understanding Genomic Decision-Making

Introduction

As genomics advances with the development of additional screening and testing procedures, it is imperative to understand how the expanding capacities of genomic science can be integrated into practice. Further, as translational science comes to the forefront in genomics, scientists and clinicians alike must assess the social, ethical, and familial implications of the increased power and availability of genomic testing. Over the course of the last 20 years, access to the genome has increased in numerous ways. As a result we have more information available to us than ever. These changes require diligent work in research and scholarship to ensure that the very best applications are safe and equitably available for those affected (Green, Guyer, & National Human Genome Research Institute, 2011).

The field of behavioral economics, the study of forces and principles behind the decision-making behaviors of humans, is growing rapidly (Madden, 2000). The field is highly focused on economic contexts; however, applications outside of a strictly economic environment are promising. Many opportunities for the application of behavioral economics have been aligned with incentivized health outcomes and health behavior changes (Bickel & Vuchinich, 2000; Hostetter & Klein, 2013; Hough, 2013). These concepts may also prove very useful in helping clinicians better understand decision-making of patients in various settings and situations. In the realm of genomic decision-making there are several opportunities for the application of behavioral economics in clinical practice that bear exploration. Although recent articles have

discussed behavioral economics and genomics, they have not fully explored the mechanisms related to genomic decision-making (Blumenthal-Barby, McGuire, & Ubel, 2014; Blumenthal-Barby, McGuire, Green, & Ubel, 2015).

It is in the setting of the patient-provider relationship where behavioral economics can be valuable. Understanding the relationship as a continuum ranging from laissez faire to authoritarian approaches, behavioral economics, when applied to decision-making, can help to balance these approaches (Bayles, 2010). Each participant enters into the patient-provider relationship with an information asymmetry-the health care provider brings the expertise and the knowledge of the clinical situation while the patient brings an abundance of knowledge about themselves, their desires, their experiences, and their lives. Behavioral economics can help to navigate the middle-ground balancing the knowledge of the provider with the needs of the decision maker (Hough, 2013). Behavioral economic approaches can open the door to conversation, which will allow for the identification and elimination of the information asymmetry that often exists in genomic decision-making encounters. This article aims, first, to introduce nurses and other health professionals to key behavioral economic concepts, providing genomics-based examples, and then to explore next steps and practice implications for behavioral economics and genomic decision-making for nursing and healthcare.

Genomic Decision-Making in a Behavioral Economic Context

Several key framing concepts from behavioral economics are important for a better understanding of the unique and often complex case of genomic decision-making. Chiefly, it is important to understand the concepts of relativity, deliberation, and choice

architecture to adequately contextualize genetic testing decisions within behavioral economics.

Relativity

Relativity, a central part of the human decision-making construct, allows for understanding the relative advantages of one option compared to others (Ariely, 2009). In exploring this concept it is important to note that the comparison must be among similar *and* available alternatives. Genomic testing may offer similar alternatives; for example, providers and patients can choose among different panels of genetic tests offering a range of levels of information including testing for additional (often related) genomic variations. This choice could be limited by insurance coverage and financial constraints, but sometimes a similar choice is available. However, genetic testing often has no alternative for relative comparison, and thus there is no comparable methodology that offers the opportunity to find out the same level of information.

The initial question for those facing decisions about genomic testing is whether to test at all. Absent alternatives, the decision is between knowing or not knowing genomic-level information and the possibility of that genomic information changing the course of care. In applying relativity to these situations there is an increase in the amount of information that is needed, specifically regarding the type, amount, and nature of the information provided by the test results and how the results may influence next steps in patient care.

There are situations where there are much more affordable and clinically expedient choices that can be made. One example is testing serum cholesterol levels

rather than doing genetic testing related to familial hypercholesterolemia (FH). Current guidelines do not recommend genetic screening evaluation of patients for FH due largely to cost (Robinson, 2013). Since there are, currently, no gene-specific treatments related to treatment of FH, knowing the specific genotype has limited value, so treatment with lifestyle, statins, and close clinical monitoring is still recommended, regardless of genetics.

Another example is the use of regular colonoscopies rather than screening for familial polyposis-related genes. A finding in a colonoscopy may itself lead to further testing, but the presence of several polyps does not establish a diagnosis of familial polyposis. Those patients who are given results from testing of polyposis-related genes might be able to better inform their practice of colonoscopy screenings. Those with genetically confirmed increased risks for familial polyposis would be best served not by general screening guidelines regarding regular use of colonoscopies, but by the use of a more frequent screening beginning at an earlier age (Syngal et al., 2015).

These two examples highlight how, in terms of relativity, comparison is very important in making genomic testing-related decisions. Currently, the genomic testing information has limited influence on the course of treatment for FH; however, with the familial polyposis there is a great difference in the screening trajectory for a patient with a confirmed increased genetic risk for polyposis.

A related concept of importance is anchoring, the strong behavioral influence produced by first impressions (Ariely, 2009). While often applied in an economic context, where first prices are found to influence willingness to spend a certain amount of

money on an item, the concept of anchoring can also be applied to health care decision-making. If a patient or a family member has had a positive experience with genomic testing, then it might encourage them to engage in genetic testing. If they have had a negative experience, then the opposite influence may be observed.

Deliberation

Deliberation, the effort by an individual to identify new alternatives, new rules, for solving a problem, becomes important when practical problem solving guidelines or heuristics-based decision tactics have failed in enabling patients or families to make decisions regarding new dilemmas (Montzavinos, 2001). Identifying prior knowledge and available evidence and applying that information when facing new problems is central to the idea of heuristic decision-making. However, as with relativity, decisions are taken in context. As the mind seeks these new alternatives, there is opportunity to address a problem through "ready-made solutions" or to apply the anecdotal knowledge of those who have encountered the same or similar situations in the past (Montzavinos, 2001, p. 39). This alternative is viable for decision-making in genetic testing, but it is also important to realize that, as with any application of the ready-made solution, the context of the individual making the decision may be different from that of the person providing the experience supporting the ready-made solution. When heuristics are inapplicable or have failed, Montzavinos asserts, the individual resorts to a deliberative approach.

The situation that one person faces in a diagnosis and testing decision is likely to differ, subtly or grossly, from the anecdotal solution. Contextually, genomic decisions are

rarely identical from patient to patient, even within families. Even though test panels and results may be the same for several people, their lives and familial, environmental, emotional, and financial contexts vary making the application of ready-made solutions difficult or impossible (Sweeny, Ghane, Legg, Huynh, & Andrews, 2014).

It seems relatively clear that there is limited potential for identifying a simple ready-made solution for decision-making in genomics. In this regard, behavioral economics may, when applied to the general situation of making decisions regarding genomic testing, prove valuable in helping patients to make the best, most informed decision, one that best aids patients. The way to best shape these processes must rely heavily on choice architecture and requires a clear understanding of several of the dynamics at play (Thaler & Sunstein, 2008).

Choice architecture

Choice architecture is the art of shaping decisions by supporting pre-existing human tendencies through designing choices within a framework that will encourage a certain choice. It is one mechanism that can be explored in attempting to best assist patients and families as they engage in genetic decision-making. There is a clear difference between choice architecture and 'manipulation' in that choice architecture merely provides guidance for decision-making without attempting to limit a person's autonomy (Sunstein, 2015). Choice architecture can address some of the external and internal contexts of decision-making with regard to genetic decisions**.** Thaler and Sunstein (2008) offer some insight on choice architecture that, when applied to genomics, further supports the unique nature of the decisions to be made.

The application of choice architecture is very well suited to encouraging patient choices regarding wellness and preventive health. In such situations, choice architects employ "nudges" to frame decisions about the most appropriate route as the easiest one without limiting options. There are numerous ways to nudge decision-makers, and often the processes are subtle because of their reliance on probable human behaviors; context is key. The scope and level of information involved in decision-making in genomics requires further exploration when contemplating nudges and choice architecture. Understanding the unique nature of genomic information will help sharpen nudge methods but also improve our understanding of their applicability in aiding patient and family member decisions – and the ethical implications of employing such methods. Key nudge tactics that warrant further exploration in the setting of genomic testing decisions include: default choices and mapping (Thaler & Sunstein, 2008).

Default choices. When no action is taken by the patient in genomic decision-making, some default choice results. This can be a slippery slope. Because the impact of genetics can extend beyond the decision maker or patient, it is imperative that any default choice be respectful and protective of all parties potentially affected by the choice. If choice architects were to use "nudges" in genetics decision-making to prompt a default choice, then perhaps the safest default would be the null, no testing, choice, one with the potential to affect the fewest people and not to impose effects on others, inadvertently or not. There are some examples where the default to test, such as the use of the newborn screening apparatus to test for a panel of specific genetic variants that can lead to disease, is established in law (National Human Genome Research Institute, 2015).

In this case, the default is set up to ensure early identification and intervention in patients with the selected genetic variants to ensure quality of life. Some of the selected variants have potential implications for other people beyond the patient (*e.g.*, the tested child's parents and other family members). The policy is designed to protect the perceived best interests of the child in order to affect change through early identification, early initiation of treatment, and improvement of clinical outcomes. In other situations, a testing default choice is not a logical standard; it would be a nudge that discourages exploring other options when faced with a new testing, not ready made, testing decision. At this time, because the implications of genetic testing results with regard to patient and family life are unclear when testing in older populations, there is no clear path to a default choice for later life genetics testing.

Mapping. Mapping can be used as a way to nudge patients when making decisions regarding genetic testing. Mapping draws on a person's knowledge and experiences to establish, by analogy to prior decision situations, a pathway to a decision in previously unexplored territory. However, as with most attempts to help shape a decision, there are some drawbacks. Not all genetic testing may lend itself directly to mapping, so it is important to be aware of the variables that may limit the ability to map out a decision pathway. These variables, fairly consistent in genomic decision-making, include the context and timing of the decision, healthcare provider biases toward one type of testing or toward not testing at all, information asymmetry creating an increased patient dependence on providers for appropriate information, and the social-emotional, and financial "costs" of genetic testing. Those patients and families considering genetic

testing may need more time to make decisions, increased knowledge sharing between providers and patients and families to limit information asymmetry, and an opportunity for deeper exploration of implications with patients to ensure that post-testing effects on patient and family lives are at least acknowledged if not mitigated in some way.

The BreastCARE intervention studies (Kaplan et al, 2014; Livuadais-Toman et al, 2015) provide an excellent example of how mapping might be helpful with genomics. BreastCARE sought to increase awareness and communication among patients and providers by using appropriate and validated measures of risk for breast cancer to structure a risk-assessment intervention. This strategy helped to increase communication of breast cancer-related information without increasing concern among patients. This intervention did not lead to a genomic testing decision per se, but it used existing knowledge to help shape the decision to speak with a provider about breast cancer. Those who undergo this intervention may, in turn need, to be assisted in making the decision to seek testing for the genes associated with breast cancer, and this too could be mapped using a similar intervention.

Next Steps for Behavioral Economics and Genomic Decision-Making

As genomic testing becomes more main stream and as more people are faced with making decisions about testing and results, it will bring new challenges to old procedures and policies. Studies of decision-making processes and concerns and of ways to facilitate decisions about testing that account for the various stakes of patients and families will be crucial in adapting existing processes and developing new approaches. Examining genetic decision-making through a behavioral economic lens allows for the exploration of

the nuanced factors in play for patients and their families in this rapidly emerging field. Work must be begun to characterize the decision-making processes undertaken by patients, family caregivers, and their healthcare providers in an effort to provide context for future studies of behavioral economic approaches in facilitating and shaping the decision-making process. While the personal and varied nature of genetic information makes restrictive and finely detailed descriptions of processes used in genomic decision-making less likely, there is a need to have a clearer understanding of any processes that are undertaken.

Incorporation of the elements of behavioral economics can also help to create a positive decision-making environment for those who are faced with these often difficult genetic testing decisions. As explored here, genomic testing is unique among medical tests because of the nature of the information and the current lack of alternatives available to get the same information. This unique nature makes the application of behavioral economics and choice architecture techniques to be of some value, but studies identifying ways to better support decision-making are imperative. Understanding if there is a decision pathway or some other tool that could be used to help patients consider the multiple variables of genomic testing is key for future steps in supporting patient decision-making.

An appreciation of the mechanisms involved in behavioral economics can assure that deciders are not forced into particular choices by the contextual forces that can disproportionately influence important decisions resulting in a choice that may not fully reflect a patient's values or represent a full deliberation of the situation. Behavioral

economics does not rest solely on the belief that humans will always act rationally in a given situation, but rather accounts for contextual influencers such as emotions, cognitive biases, and other internal and external pressures (Ariely, 2009). There must, therefore, be a better understanding influence of the social, emotional, and financial costs has on medical decision-making, and more specifically genomic decision-making. There is a wide range of variables that each person will uniquely encounter, but there are also many commonalities that must be accounted for and further explored (Lerner, Li, Valdesolo, & Kassam, 2015). One behavioral economic concept that has been noted is the present-centeredness, termed "present bias," that shapes decision-making (Hostetter & Klein, 2013). Awareness of present bias is important in understanding how costs are perceived when making decisions. Understanding the value of information at the moment of testing and understanding the possible implications for future decisions of the patient and the patient's family is imperative in assisting with decision-making.

It is important to consider how behavioral economic concepts can be applied in clinical practice. In the current patient-centered care environment, nursing has a unique role in patients' decision-making processes. Relationships with patients and their families in times of illness and wellness place nurses in the context of making important decisions. Often nurses are seen as a source of information and clarification when communication with physicians or specialists is limited. Nurses and other healthcare professionals must seek to better understand the context of the care that they are delivering to their patients. The behavioral economic concepts described in this article offer a good start for better understanding decision-making, specifically in a genomic

context. Beyond the genomic focus of this article, nurses can benefit from further exploring these concepts, understanding how their own practices may inadvertently influence patient and family decisions, and incorporating some of these approaches in supporting patients and families as they make difficult decisions.

While these behavioral economic concepts do bring a new lens to the work that must be done regarding genetic decision-making, they do not replace the key concepts that are embodied in high quality health care provision. It is important to keep these professional and ethical standards in mind as decision-making work is undertaken. Patients are more than the sum of their complaints, diseases, or syndromes, and the process of diagnosis and treatment of illness is complex and multifaceted, possibly even more so when genomics are involved (Gorovitz, 2010). The use of the behavioral economic mechanisms to support patient decision-making is helpful in managing the complexities of these decisions through the use of information and expertise while still respecting autonomy of patients and families. This is the essence of the marriage of behavioral economics with the patient-provider relationship—the use of these approaches to overcome the asymmetry of information that often exists through thoughtful and deliberate support of patient decision-making.

Continued interdisciplinary, collaborative exploration of decision-making is an important part of assuring that patient decision-making with regard to genomics is supported to the highest possible level. Understanding the core concepts of behavioral economics and choice architecture is key in this endeavor, and the use of these concepts

to inform future studies will allow for improvement of the patient experience in genomic decision-making.

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CHAPTER THREE:

PERSONAL GENOMIC TESTING: UNDERSTANDING AGE GROUP DIFFERENCES IN GENETIC KNOWLEDGE, PERCEPTIONS, AND DECISION-MAKING

Abstract

Purpose of The Study: This study describes differences among three age groups (19-39, 40-59, 60+ years old) who are new customers of direct-to-consumer personal genomic testing (DTC PGT) in their knowledge and perceptions of genetics as well as factors that influence their decisions to test.

Design and Methods: This analysis of the Impact of Personal Genomics Study used a sample of 887 study participants who were surveyed three times via online survey (baseline [before receiving results], 2-3 weeks after receiving results, and 6 months after receiving results). ANOVA was used to evaluate change in means of Genetic Knowledge, Self-Rated Genetic Competency, Personal Genetic Utility, and Genetic Response Efficacy over time and also across the three age groups. Factor analysis was used to identify factors related to the decision to engage in DTC PGT.

Results: For Genetics Knowledge and Personal Genetic Utility scores, the 60+ year old group had significantly lower scores when compared with the other two age groups. Factor analysis identified two strongly loading factors with themes of 'Health and Future' and 'Curiosity and Intrigue' oriented items. There was a significantly lower mean 'health and future' score among the older adult population.

Implications: While the sample for this study was drawn from DTC PGT customers, these results support previous understandings that older adults have different views of

genetic and genomic testing than the younger age groups. Differences among the age groups support the need for further study and evaluation of approaches to meet the unique needs of older adults when it comes to genomic testing and understanding the value and use of genomic results. As the aging population grows and their care is guided by genomic testing, these areas of age group differences may hold a place in helping to design interventions to support and engage older adults in their precision care.

Keywords: *decision factors, genetic testing, genetic knowledge, older adults*

Personal Genomic Testing: Understanding Age Group Differences in Genetic Knowledge, Perceptions, and Decision-Making

Introduction

The drive to make healthcare a personalized, precision science means that individual complexities will be very influential in tailoring interventions. Genomics and genetics are part of the science that will shape the personalization of medical care. As work in health sciences moves closer to precision medicine, the personal context in which healthcare encounters occur is becoming more important (Bayliss et al, 2014). Understanding the contextual factors and influencers of patient decision-making behaviors is an important part of understanding personal contexts and is key in helping to support patient decision-making. While underlying genetic knowledge is important, the existence of other contextual factors such as perception of genetics, response efficacy, and genetic utility may also offer some important insight into decision-making. The purpose of this study is to explore differences among three age groups in genetic knowledge, perceptions, and decision-making influencers.

There has been limited study specifically about the knowledge and perceptions of older adults related to genetics and genomics. Among those few studies, older adults have demonstrated a willingness to participate in genetic testing if it demonstrates value and has promise for illness prevention or benefit for future generations (Skirton et al., 2005). Older adults also identified the importance of family involvement and clarity of testing purpose (Frazier et al., 2006). Several quantitative studies have reported some age-related differences with regard to knowledge and beliefs. Older adults have been found to have lower genetic knowledge scores when compared with other age groups (Ashida et

al., 2011; Carere et al., 2015; Morren et al., 2007). Additionally, some differences in beliefs about genetic causes of weight and obesity have been associated with differences in age (Ashida et al.). A significantly lower comprehension of genetic results has been noted among older adults when compared with younger adult groups (Ostergren et al., 2015).

Genetic Decision-Making

An understanding of how decisions are made regarding genetic testing can help health care providers and genetic counselors improve their facilitation of patient and family decision-making. In the early years of prenatal diagnosis and pre-conception genetics, clinical professionals and medical ethicists identified the need to support individualized decision-making related to genetics (Pauker, 2013; Paulsen et al., 2013). The research-based descriptions of decision-making of patients with regard to predictive genetics addressed ideas and questions, such as: How has a treatment option been developed? Is treatment curative or palliative in nature? If treatment is unavailable, does testing offer some opportunity to decrease ambiguity? Does genetic information impact reproduction decisions? Could genetic information assist other family members? (Henderson, Maguire, Gray, & Morrison, 2006; Katz, Kurian, Morrow, 2015; Paulsen et al.).

The study of decision-making is very common in gene-linked cancer diagnosis and treatment (Iredale et al., 2008; McQuirter et al., 2010; Sames, 2008). The understanding of gene significance in hereditary breast cancer has brought increased focus on decision-making and decision aids for patients with BRCA1 and BRCA2

mutation-linked familial breast cancer. In Iredale, et al.'s study, the complexity of decision-making and familial breast cancer changes as the level of risk changes for the patient. A common element, however, was a desire for discussions of preventive and lifestyle related information that does not offer false hope (Iredale, et al., 2008). The desires of the participants (breast cancer patients) for specific types of information were also different when compared among risk-groups. The participants were sensitive to their own concerns and also the perceived preferences of healthcare professionals when choosing among treatments. While these tests are more targeted, education about risks and limitations regarding genetic analysis of the whole genome helps to decrease uncertainty and decisional conflict (Sanderson et al., 2013).

Familial linkage and the witnessed experiences of their relatives' having cancer are driving factors for making the decision to seek out prophylactic mastectomy as a method of seeking control among people at risk for breast cancer (McQuirter et al., 2010). The process is unique to each woman, because of her previous experiences and her life situation at the time of making the decision (McQuirter et al.). Multiple concerns influence patient decisions, including previous personal or familial experiences with cancer; and the desire to have some control over decisions, personal image, provider recommendation, and support. While some of these concerns are truly specific to mastectomy decisions, many can be generalized to the population of patients with BRCA1 and BRCA2 mutations at the very least. Focusing on a treatment decision in response to genetic findings, McQuirter and colleagues offer insight into the same areas

of concern (*e.g.*, the value of testing; influence on family members) other patients contemplating genetic testing or facing unfavorable genetic results may encounter.

While there has been a strong history of paternalistic directives by health care professionals in genetic decision-making, there is an increased involvement of patients in decisions related to genetic testing. In the study of cancer, specifically breast cancer diagnoses, there is an increased reliance on patient preferences (Katz et al., 2015). One important aspect of increased patient involvement is ensuring that patients are aware and accepting of the extended implications of the genetic information on patients' relatives and possibly future cancer diagnoses. This increased involvement of patients is also associated with an increased use of genetic technologies in patient care across multiple cancers, not just limited to breast cancer.

Decision-Making Among Older Adults

Gerontologists and geriatricians encourage preservation of autonomy and control in older adult patients (Mallers, Claver, & Lares, 2014). When older patients are supported in maintaining control over decisions, they are more successful through the aging process and have better outcomes (Mallers et al.). The study of decision-making in older adults is emerging on the health care forefront. In light of the importance of autonomy to older patients, an emphasis to better understand the value older adults place on shared decision-making in the health care setting is needed. The underpinning concepts of shared decision-making (e.g., information exchange, deliberation regarding preferences, and developing agreement between patient and provider) were very similar to the desires that the older adults had for their interactions with providers (Burton et al.,

2015; Naik et al., 2005). The level of information sought varies by patient; however, most favor the provision of limited amounts of information (Burton et al.). Deliberative capacities have been found to be lower among older adults than younger adults when dealing with new information; however older adults demonstrated a preservation of affective abilities when dealing with experience based decision-making (Huang, Wood, Berger, & Hanoch, 2015).

In summary, the current understanding of genomic decision-making among older adults is limited. The differences among the age groups that have been identified are in genetic knowledge and perceptions of gene-obesity linkages. Genetic testing decision-making has, in general, been found to be associated with the level of information and provider perspective, but there are limited studies of the older adult populations with regard to genetic decision-making. In general, it is important for older adults to be involved in their own decision-making; however, older adults may need more support when they engage in information processing and decision-making related to costs and benefits and are presented with information about a new or unfamiliar decisional situation.

While genetic knowledge has been shown to differ among age groups, the other contextual factors and motives that influence decision-making may also differ among age groups. There are no studies that explore those differences across the age groups. In this study we sought to investigate these age differences by answering two questions through secondary analysis of the Impact of Personal Genomics (PGen) data: 1) What are older adults' perceptions regarding genetic testing and genetic information as compared to

other age groups? 2) What influences decision-making of older adults when deciding to engage in direct-to-consumer personal genomic testing (DTC PGT) as compared to other age groups?

Design and Methods

The PGen study was approved by the Partners Human Research Committee and the University of Michigan School of Public Health Institutional Review Board. Each participant completed an electronic informed consent prior to being enrolled. Details of design and data collection for the PGen study have been reported previously (Carere et al., 2014; Lehmann et al., 2012).

The sample was recruited between March and July 2012 from new customers of 23andMe and Pathway Genomics, two independent DTC PGT agencies, after they placed an order for genomic testing. Participants in the study were asked to complete three online surveys administered by Survey Sciences Group (Ann Arbor, MI). The three surveys included a baseline survey which was administered after submission of the sample but prior to receipt of DTC PGT results, two to three week follow up after receipt of DTC PGT results, and six-month follow up after receipt of DTC PGT results.

Sample

The total sample for the PGen study included 1,464 participants who engaged in DTC PGT. The sample used for this study consisted of the 887 participants who participated in all three of the surveys and completed all analyzed items and scales. These 887 participants were split into three age groups, 19-39 year olds, 40-59 year olds, and 60+ year olds. This division was based on other studies with the data set (Ostergren et al.

2015). Demographic characteristics for the 887 individuals included in our study are depicted in Table 3.1.

Table 3.1
Demographic and Socioeconomic Characteristics by Age Group (%)

Age Group (years)	19-39	40-59	60+	Overall
Number	350	314	223	887
Mean Age (years)	30.22	49.51	66.92	46.28
Female	56.9	64.1	56.1	59.2
Relationship status				
Single	36.3	14.6	5.4	20.8
Married/Partnered	58.6	71.5	75.8	67.4
Divorced/Separated/Widowed	5.1	14.0	18.9	11.7
Adopted	6.0	7.9	2.2	5.7
Have Biological Children	18.9	60.6	78.5	48.6
Ethnicity				
Hispanic/Latino	6.9	5.1	1.3	4.8
Race[a]				
Asian	9.7	2.2	0.0	4.6
Black or African American	3.7	3.8	1.3	3.2
White	86.6	92.4	95.5	90.9
Other Race	11.9	7.0	7.1	9.0
Highest Level of Education				
Less Than College	17.2	20.7	25.1	20.4
College Degree	37.1	31.1	17.9	30.2
Some Graduate School	35.1	34.2	40.0	36.0
Doctoral Equivalent	10.5	14.0	17.0	13.5
Income in the past 12 Months				
<$100,000	58.9	48.4	58.4	55.9
$100,000-199,999	29.1	36.3	28.1	31.4
≥$200,000	10.0	15.3	13.6	12.8

Note: [a]Some participants indicated more than one race thus the totals exceed 100%.

Measures

The major variables of interest in this study include: Genetic Knowledge (GK), Self-Rated Genetic Competency (SRGC), Genetic Personal Utility (GPU), and Genetic Response Efficacy (GRE). The term genetic knowledge describes the factual science, familial inheritance, and technology information related to genetics and genomics as it is

known to the respondent. In this study, genetic knowledge is measured using a nine-item, true or false instrument that is a combination of selected items from previous studies of genetic knowledge (Bowling et al., 2008; Furr & Kelly, 1999; Molster, Charles, Samanek, & O'Leary, 2009; Smerecnik, 2010). Genetic knowledge is measured at baseline and at the six-month follow up, and is expressed as a percentage of correct answers.

The SRGC Scale is composed of five seven-option Likert type items that evaluate a respondent's beliefs in their own ability to understand genetic information. The SRGC Scale was administered at baseline and at the six month follow up, higher scores indicate stronger beliefs in their own abilities. The Genetic Personal Utility Scale (GPUS) is composed of three questions with a five-option Likert-type scale (Bloss et al., 2010). These GPUS questions are asked in the two to three week follow up and six-month follow-up questionnaires. The GPUS questions address a respondent's perception of the usefulness of the genetic testing results regarding their health. Higher scores indicate a greater perceptions of usefulness. A five-option Likert-type single item is used to measure GRE in respondents (Wade et al., 2012). The item is included in the baseline and six-month follow-up questionnaires, a higher score indicates greater belief that genetic testing has benefits for improving or maintaining health.

Statistical Analysis

A mixed between-within subjects, repeated measures analysis of variance (ANOVA) was used to compare the changes between initial and follow-up measures of Genetic Knowledge, Genetic Response Efficacy, Self-Rated Genetic Competency, and

Genetic Personal Utility among the three age groups. When homogeneity of covariance was not satisfied, Pillai's Trace was used to increase the robustness and power of the analysis. Bonferroni corrections were conducted for post hoc analyses when appropriate.

In order to identify genetic testing decision-making influencers, participant ratings of importance for 19 aspects of genetic testing were evaluated by factor analysis with Oblimin (Oblique) rotation to identify any scoring patterns among the sample. The means of the three age groups for the resulting factors were compared using ANOVA. When homogeneity of variance was not satisfied, Welch's adjusted *F* ratio was evaluated, correcting for inequalities in variance among groups (Welch, 1951). In addition, Games-Howell post hoc tests were performed using an *a priori* alpha level of .05. Analyses were conducted using IBM SPSS Statistics, Version 23.0.

Results

Descriptive statistics for Genetic Knowledge, Self-Rated Genetic Competency, Genetic Response Efficacy, and Genetic Personal Utility are presented in Table 3.2.

Table 3.2
Genetic Knowledge, Perceptions, and Beliefs Descriptive Statistics by Age Group

Scale	19-39 years	40-59 years	60+ years	Overall
Genetic Knowledge				
Baseline	92.00 (9.56)	90.90 (10.69)	88.99 (11.16)	90.85 (10.44)
6 month follow-up	92.95 (9.28)	91.85 (9.54)	89.89 (11.46)	91.79 (10.02)
Self-rated Genetic Competency				
Baseline	5.80 (1.17)	5.85 (1.13)	5.81 (0.97)	5.82 (1.10)
6 month follow-up	5.63 (1.10)	5.59 (1.11)	5.35 (1.05)	5.55 (1.09)
Genetic Personal Utility				
2-3 week follow-up	3.96 (0.77)	3.92 (0.86)	3.76 (0.98)	3.89 (0.86)
6 month follow-up	3.69 (0.90)	3.77 (0.95)	3.58 (1.05)	3.69 (0.96)
Genetic Response Efficacy				
Baseline	3.49 (0.98)	3.43 (0.97)	3.37 (0.94)	3.44 (0.97)
6 month follow-up	3.23 (1.05)	3.42 (1.09)	3.22 (1.13)	3.30 (1.09)

Note: Values expressed as Mean (SD)

Comparing Genetic Knowledge and Perceptions Measures Among Age Groups

There was not a significant interaction between time and age group membership on genetic knowledge scores, F (2, 885) = 0.002, p = .998. There was a significant effect of time on genetic knowledge, F (1, 886) = 5.749, p = .017. All of the age groups showed an increase in genetic knowledge scores between the baseline and six month follow-up surveys. Age group membership had a significant effect on differences in genetic knowledge scores, F (2, 885) = 8.862, p < .001**.** Post hoc analyses indicated a significant difference in change in genetic knowledge scores when comparing the 60 + year old group with both the 19-39 year old group (M=.274, 95% CI [.118, .430], p<.001) and the 40-59 year old group (M=.174, 95% CI [.015, .334], p<.05).

There was a significant interaction effect for time and age group membership on SRGC, F (2, 885) = 4.169, p = .016. Post hoc tests show no difference in means between the 19-39 year old and 40-59 year old groups (M=.000, 95% CI [-.173, .172], p=1.00) while there was a difference between the 60+ year old group and the 19-39 year old group (M=.135, 95% CI [-.325, .055], p<.269) and the 40-59 year old group (M=.135, 95% CI [-.329, .059], p<.288). There was also a significant effect of time on SRGC, F (1, 886) = 55.159, p<.001. All of the SRGC scores decreased over time regardless of the age group. Age group membership was not significant, F (2, 885) = 1.772, p = .171.

There was also a significant interaction effect for time and age group membership on GRE, F (2, 885) = 3.523, p = .030. The main effect for time on GRE was significant, F (1, 886) = 11.175, p = .001. Genetic Response Efficacy scores were higher at baseline than they were after six months, regardless of age group. There was no significant main effect for age group membership on GRE, F (2, 885) = 1.705, p = .182.

The interaction effect for time and age group membership on GPUS was not significant, F (2, 885) = 2.045, p = .130. However, there was a significant effect for time on GPUS, F (1, 886) = 59.450, p < .001, the scores for GPUS were higher at the two to three week survey than at the six month follow up. There was also a significant effect for age group membership, F (2, 885) = 3.307, p = .037. There were significant differences between the 60+ year olds and both the 19- 39 year olds (M=.155, 95% CI [.016, .294], p<.029) and the 40-59 year olds (M=.174, 95% CI [.031, .316], p<.017), indicating that the GPUS scores for the 60+ year olds were significantly lower than both of the other age groups.

Examining Patterns in Decision-making Influences

The 19 items that focused on reasons to test and factors influencing testing decisions were subjected to factor analysis. The screeplot illustrated a clear break after the second factor. Using Catell's (1966) scree test, it was decided to retain two factors for further evaluation. Table 3.3 illustrates the pattern and structure matrices for the two-factor solution with a 0.4 pattern coefficient cut off.

The two-factor solution explained a total of 32.8% of variance, with Factor 1 contributing 22.3%, and Factor 2 contributing 10.5%. The rotated solution revealed the presence of simple structure (Thurstone, 1947), with both factors showing a number of strong loadings and each variable loading substantially onto only one factor.

The interpretation of the two factors identified two unique patterns to the loadings. Items focused on health and the future loaded strongly onto Factor 1. Items more aligned with the curiosity and intrigue of genetics loaded strongly onto Factor 2. There was a weak correlation between the two factors (r = .203). These results suggest that the components can be evaluated separately. Two factor scores were created by averaging the items from each factor.

Table 3.3

Pattern and Structure Matrix for Factor Analysis with Oblimin Rotation

	Survey Item	Pattern coefficients Factor 1	Pattern coefficients Factor 2	Structure coefficients Factor 1	Structure coefficients Factor 2	Communalities
Health and Future	• **Improve my health**	**.812**	-.052	**.801**	.113	.645
	• **Create a better plan for the future**	**.780**	-.033	**.773**	.125	.598
	• **Finding out about personal risk for specific diseases**	**.779**	-.134	**.769**	.150	.583
	• **Health-related**	**.771**	-.007	**.752**	.024	.592
	• **Predict whether or not I'm going to get a particular disease**	**.693**	-.018	**.689**	.122	.475
	• **Individual response to different types of medications**	**.680**	-.003	**.679**	.135	.461
Curiosity and Intrigue	• **Personal interest in genetics in general**	-.098	**.557**	.015	**.538**	.298
	• **The convenience of being tested at home**	.037	**.526**	.143	**.533**	.286
	• **The education materials made available through the company**	.116	**.508**	.219	**.531**	.295
	• **Desire to learn more about my genetics because I am adopted**	.118	**.494**	.218	**.518**	.282
	• **Curiosity about my genetic makeup**	-.081	**.478**	.016	**.462**	.219
	• **The service seemed like it would be fun and entertaining**	-.311	**.455**	.345	**.447**	.247
Non-Loading	• Might receive unwanted information	.372	.078	.419	.378	.156
	• Information about the risk for my current or future children	.358	.305	.388	.153	.265
	• Privacy of my genetic information	.227	.128	.253	.174	.080
	• Other members of my family are using personal genomic services	.021	.396	.297	.415	.161
	• Learn about my genetics because I have limited information about family health history	.266	.394	.101	.400	.268
	• Learn about my genetic makeup without going through a physician	.222	.369	-.219	.392	.219
	• Cost of services	-.018	.321	.047	.317	.101

Note: Major loadings for each item included in factors are bolded.

Age group membership was examined for the two factors using ANOVA. Descriptive statistics for each of the factors for the age groups and overall are found in Table 3.4. Though the assumption of homogeneity of variance was not satisfied. The effect of age group membership was significant, *Welch's F* (2, 513.34) = 5.012, $p < .01$. Post hoc tests indicated that the mean scores for the 60+ year old age group were significantly different from the 19-39 year old and 40-59 year old groups for the Health and Future Factor ($p = .006$ and $p = .028$ respectively). There was not a significant difference in the Curiosity and Intrigue scores for the three age groups: *F* (2, 884) = 2.011, $p = .134$.

Table 3.4

Descriptive Statistics for Two Factors by Age Group

	19-39 years old	40-59 years old	60+ years old	Overall
Health and Future	2.37 (0.46)	2.36 (0.51)	2.23 (0.60)	2.33 (0.52)
Curiosity and Intrigue	2.47 (0.40)	2.41 (0.41)	2.47 (0.41)	2.45 (0.41)

Note. Values expressed as Mean (SD)

Discussion

When examining the differences among age groups related to genetic knowledge, perceptions, and factors that shape decision-making there are differences between the 60+ year old group and the younger age groups. Older adults were found to have significantly lower genetic knowledge scores, and age group membership was also found to be a significant factor in differences in perceptions of genetic utility. Self-rated genetic competency, and genetic personal utility measures had significant decreases over time, while Genetic Knowledge increased significantly over time. Thus there were differences in perceptions of genetics among older adult participants in the PGen study when

compared with other age groups. The factors that influenced the decision to engage in DTC PGT loaded into two factors, 'Health and Future' and 'Curiosity and Intrigue.' Older adult groups had significantly lower scores in the 'Health and Future' factor, indicating that older adults may be less likely to be concerned with the 'Health and Future' aspects of testing than the other age groups. This may be an effect of fatalism on the part of older adults, or perhaps they do not place a high value on the future possibilities for genetic information on their own health.

The results of this study further support previous studies' assertions that there are clear differences in genetic knowledge among different age groups (Ashida et al., 2011; Carere et al., 2015; Morren et al., 2007; Ostergren et al., 2015). The results of comparisons of genetic knowledge show that the 60+ year olds were more likely to have statistically significant lower genetic knowledge scores than the other two groups. As previously discussed, these findings could be associated with limited genetics education exposure even with 57% of this age group reporting having had some graduate education. These results must be examined in the overall change that is exhibited in knowledge, the change is scores, while statistically significant, is not necessarily a meaningful change as it is small in comparison to the overall scoring for the genetic knowledge questions. Even in light of this, the finding highlights the need to seek out opportunities and methods to educate older adults about genetics so that they are better able to engage with the genetic technology that is becoming more available in society clinically and commercially.

The decreases of the Self-Rated Genetic Competency scores over time may indicate that the experience of using DTC PGT may have led the participants to

reconsider their abilities to interpret the genetic material. Response Efficacy measures also decreased over time, possibly indicating that the receipt of the DTC PGT results may have caused the study participants to change their views on the ability of genetic level information to improve their health. This change could also be related to the fact that their DTC PGT results may not have any genomic findings that were new to the participants or that they felt like they could do anything about after receiving the results.

There was also a statistically significant decrease in the respondents' GPUS scores. The decrease of the means of these scores across all three age groups does suggest that there may be a feeling of inability to connect the PGT results directly to health actions among all age groups. Further study is needed to better understand this possibility. It would be very interesting to understand if the decrease in the personal utility scale scores relates to specific factors or is the decrease a result of a failure to meet the participants' anticipated utility prior to receiving the results.

While understanding the knowledge and perception differences among the three age groups is helpful, in order to move a step closer to the actual decision-making process, it is important to understand the driving motivations for engaging in DTC PGT. The identification of the two factors capturing the participants' reasons to test is important because it highlights two distinct areas of interest that were unique among the participants. The Health and Future-Oriented factor was the stronger loading factor, highlighting the importance that participants placed on the health-related aspects of the genomic testing. The second factor is best characterized as being Curiosity and Intrigue-Oriented which captures the elements of DTC PGT that are more related to the novelty

and, to some extent, recreational engagement that some participants find most appealing. When these two factors are compared across the age groups, the 60+ year old group was significantly less likely to rate the Health and Future-related aspects of DTC PGT as high as the other two age groups were. This finding may be tied with the differences seen in the genetic knowledge score among the age groups; however, it is also possible that there are other factors of importance to older adults that were not captured by the surveys. When looking at the second factor scores, 'Curiosity and Intrigue,' there is no statistical difference among the three age groups. This may be a result of the fact that this test is not being completed in a clinical setting and that the aspects captured by this factor are baseline aspects that all participants in DTC PGT find important. Both of these factors could be examined more completely in an effort to fully understand what drives participants to engage in the DTC PGT.

The use of the PGen data set provides great benefits in providing a high quality repeated measures survey study with a large sample of respondents for the exploration of these questions, although it should be noted that there are several limitations of the study that must be acknowledged. First and foremost, these results give some insight into the different age groups, but they are somewhat limited in their broader application because of the fact that the sample is predominantly white (90.9%), married/partnered (67.4%), largely female (59.2%) and affluent (44.1% reporting annual earnings > $100,000). It is also imperative to realize that the entire sample is self-selected. Translation of these findings will require other study designs, more diverse populations, and comparisons of the findings to better support generalizable research findings.

In conclusion, there are significant differences in the genetic knowledge and perceptions of the 60+ year old age group when compared with the 19-39 year old and 40-59 year old age groups. These differences, even while observed in this group of DTC PGT participants, offer some clear indications that more research on the older adult population with regard to genetics and genomics knowledge, perceptions, and decision-making needs to be done. Furthermore, there is a need for similar studies to examine those persons who are engaging in clinical genetic or genomic testing programs beyond DTC PGT.

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CHAPTER FOUR:

USING AGE AND PROTECTION MOTIVATION THEORY TO EXPLORE PERSONAL GENOMIC TESTING RESULT UTILIZATION

Abstract

Background: Direct-to-consumer personal genomic testing (DTC PGT) is changing the way that people are able to access genetic level information. Testing results from DTC PGT companies come in a different format than those from clinical testing and healthcare providers. Consumers who use DTC PGT are getting the genetic-level information and are sometimes making social and financial health-related decisions based on their own perceptions of the meanings of the results.

Objectives: To explore the use of the Protection Motivation Theory (PMT) concepts as a way to better understand behaviors of results utilization in DTC PGT customers through looking at trends among three age groups.

Methods: We analyzed data from the Impact of Personal Genomics Study, which were collected before DTC PGT results were received, and again at two to three week and six month follow-up intervals following participants' receipt of DTC PGT results. Contingency tables and descriptive statistics were used to examine trends in PMT concepts and uses of DTC PGT results among three age groups. Four outcomes were examined: 1) discussing DTC PGT results with someone, 2) making changes in health insurance, 3) making changes in financial or retirement plans, and 4) making changes in advance planning.

Results: Those who engaged in making changes to their retirement and advance directives were more likely to be of the 60+ group than any other group. There were no

large differences in the ratings of the PMT theory concepts, those who engaged in the four target behaviors were more likely to have higher response efficacy and self-efficacy ratings while having moderate to lower perceived severity ratings and moderate to higher perceived vulnerability ratings.

Conclusions: The significance of the application of the PMT is valuable in helping to better understand who and, possibly in the future, why some DTC PGT participants are responding the way that they do to their DTC PGT results. These results can help to support DTC PGT participants in decision-making by offering a better understanding about what drives their decisions. These findings also suggest that DTC PGT results are being used when making decisions that are important including, financial and advance planning decisions. The link between perceptions of results and self and these outcomes is important in further describing the context of decision-making in genomics and across age groups.

Keywords: *Protection Motivation Theory, Direct-to-Consumer Personal Genetic Testing, Genetics, Advance Planning, Genomics*

Using Age and Protection Motivation Theory to Explore Personal Genomic Testing Result Utilization

Introduction

As genetic information has become a larger part of the health landscape, there have been numerous policy and guideline changes that are intended to address concerns about privacy and discrimination related to genetic findings (eg. Genetic Information Nondiscrimination Act 2008) (Green, Lautenbach, & McGuire, 2015). Direct-to-consumer personal genomic testing (DTC PGT) carries with it a variety of similar and also unique concerns when compared with clinical genetic testing. Direct-to-consumer personal genomic testing services do not provide individualized genetic counseling to accompany their results, and while the testing services do offer education related to testing and results, the service model leaves open the possibility of misinterpretation on the part of the result recipients. There have been several studies to emerge from the Impact of Personal Genomics (PGen) data that indicate differences in various aspects of consumer understanding, knowledge, and comfort with the genetic information (Carere et al., 2014; Carere, VanderWeele, et al., 2015; Ostergren et al., 2015). Understanding the way that genomic testing results may lead to changes in health behaviors is an important part of evaluating the full influence of genomic level information (Christensen et al., 2015; Zick et al., 2005). Furthermore, understanding how consumers' perceptions related to genomics may influence the actions they take with their genomic information may assist healthcare providers, policy makers, and scientists to better understand and support individuals who engage in DTC PGT (Kaufman, Bollinger, Dvoskin, & Scott, 2012; McBride et al., 2009; McBride, Wade, & Kaphingst, 2010). Previous studies have

examined the influence of genetic testing on individuals' purchasing of insurance or management decisions and have reported mixed findings (Armstrong et al., 2003; Zick, Smith, Mayer, & Botkin, 2000; Zick et al., 2005). Those previous studies did not, however, consider the perceptions or the ages of the participants as indicators of these behaviors, nor did they study DTC PGT. This article evaluates differences in the DTC PGT result utilization behaviors as they differ among different age groups (19-39, 40-59, and 60+). It also explores the use of the Protection Motivation Theory (PMT) (Maddux & Rogers, 1983; Rogers 1983) as a way to explain the result utilization behaviors of DTC PGT customers.

Protection Motivation Theory

The PMT, in its revised version, features three main concepts: threat appraisal, coping appraisal, and protection motivation (Floyd, Prentice-Dunn, & Rogers, 2000; Maddox & Rogers, 1983; Norman, Boer, & Seydel, 2005; Rogers, 1983). Threat appraisal is best described as the combination of the perceived severity and the perceived vulnerability related to the negative outcome of concern (Rogers, 1983). This negative outcome could be a disease diagnosis, injury, or some other negative experience that can be avoided. Perceived severity is defined in terms of a person's beliefs about the potential bodily harm, interpersonal threats, and intrapersonal threats that would result from the negative outcome. Perceived vulnerability is defined in terms of a person's beliefs that they may experience the negative outcome.

Coping appraisal is described as the combination of perceived self-efficacy and response efficacy related to the negative outcome of concern (Maddox & Rogers, 1983;

Rogers, 1983). Response efficacy is defined as a person's beliefs related to the effectiveness of coping responses. Self-efficacy is defined as a person's beliefs about their ability to perform or not perform a behavior (e.g., a recommended response to the negative outcome of concern).

Protection motivation is best described as the intent to adopt a recommended course of action or engage in a protective behavior to limit the likelihood of experiencing the negative outcome (Maddux & Rogers, 1983; Rogers, 1975, 1983). The PMT is based on the assumption that there is a positive linear relationship among: severity of the threat, vulnerability to the threat, the ability to cope with the threat, and that engaging in the behavior of concern will decrease risks of the negative outcome (Rogers, 1983). For the purposes of this study, protection motivation is defined as engaging in disclosure of results or making changes in insurance, retirement or financial plans, or advance planning.

Protection Motivation Theory and Genetics

Protection motivation theory has been applied to a variety of studies, several of which have genetic relevance either directly with genetic testing, genetic information, or by featuring some aspect of family inheritance of diseases (Azzarello, Dessureault, & Jacobsen, 2006; Fisher, Bonner, Biankin, & Juraskova, 2012; Helmes 2002; Ralph et al., 2014; Vadaparampil et al. 2004; Wright, French, Weinman, & Marteau, 2006). Three distinct areas of behaviors that have been studied using the PMT with relevance to this study include: screening and preventive behaviors, use of genetic testing information to make health changes, and engagement in genetic testing.

In the area of screening and preventive behaviors, self-efficacy and perceived risk were found to be significant contributors to making changes in preventative health behaviors related to melanoma. (Azzarello, Dessureault, & Jacobsen, 2006). In a population of first-degree relatives of men with prostate cancer, self-efficacy, income and age were found to be contributors to making changes (Vadaparampil et al. 2004). These findings were consistent with the results of other research in health-protective behaviors. In examining the influence of genetic risk on smoking, self-efficacy was shown to have a significant effect on intentions to quit smoking (Wright, French, Weinman, & Marteau, 2006). Among smokers, knowledge of increased genetic risk for lung cancer is associated with greater intentions to engage in smoking cessation activities when compared with those without any genetic risk knowledge. Protection Motivation Theory has also been applied to the preference for selective estrogen reuptake modulators (SERM) among women with an increased genetic risk of breast cancer. Ralph and associates (2014) evaluated the relationships among PMT concepts and intentions to engage in SERM treatment identifying perceived vulnerability, perceived severity, and response efficacy as each making a significant unique contribution to the explained variance.

Helmes (2002) assessed the PMT's components for predictive applications in understanding womens' motivations to engage in genetic testing. The study did not fully support the use of the PMT as a predictive framework for genetic testing motivation assessment; however, there was a clear association with perceived risk and an increased likelihood to engage in testing. Fisher, Bonner, Biankin, and Juraskova (2012) evaluated the application of PMT constructs as possible predictors of whole genome sequencing

(WGS) screening intentions; finding that response efficacy, response costs, and self-efficacy each made a significant unique contribution to explained variance in the model.

The PMT has been applied to a variety of genetic and genomic-related behaviors, but there is limited assessment of PMT's applicability to DTC PGT, specifically the disclosure of DTC PGT results or utilization of the DTC PGT results to make changes in insurance, retirement, and advance planning behaviors. These areas are not currently addressed in the literature. This study explores the application of the PMT to genetic information disclosure and utilization behaviors among three age groups (19-39, 40-59, 60+). Our aim for this article is to explore the applicability of the PMT to the utilization of DTC PGT results, and to describe age group differences in use of the DTC PGT results.

Design and Methods

Sample

The PGen study was approved by the University of Michigan School of Public Health Institutional Review Board and the Partners Human Research Committee. Each study participant completed an electronic informed consent prior to study enrollment. The specific details of design and data collection for the PGen study have been reported previously (Carere et al., 2014; Lehmann et al., 2012).

The sample was recruited between March and July 2012 from among new direct-to-consumer genomic testing customers of the 23andMe and Pathway Genomics services. The study consisted of three online surveys that were administered by Survey Sciences Group (Ann Arbor, MI). These surveys included a baseline survey that was administered

following the participant's submission of a sample but prior to receipt of DTC PGT results, the two follow-up surveys were administered at two to three weeks and six-months after receipt of the DTC PGT results.

Table 4.1
Demographic and Socioeconomic Information by Group (%)

	19-39 Years	40-59 Years	60+ Years	Overall
Number	350	314	223	888
Mean Age (years)	30.22	49.51	66.92	46.28
Female	56.9	64.1	56.1	59.2
Relationship status				
Married/Partnered	58.6	71.5	75.8	67.4
Have Biological Children	18.9	60.6	78.5	48.6
Race[a]				
American Indian/Native	3.1	1.9	3.6	2.8
Alaskan	9.7	2.2	.0	4.6
Asian	3.7	3.8	1.3	3.2
Black or African American	1.4	.3	.4	.8
Hawaiian or Pacific Islander	86.6	92.4	95.5	90.9
White	7.4	4.8	3.1	5.4
Other Race				
Highest Level of Education	17.2	20.7	25.1	20.4
Less Than College	37.1	31.1	17.9	30.2
College Degree	35.1	34.2	40.0	36.0
Some Graduate School	10.5	14.0	17.0	13.5
Doctoral Equivalent				
Current Employment Status	81.2	78.4	39.0	69.6
Employed	.6	11.1	63.2	20.0
Retired	12.6	16.5	6.3	12.4
Unemployed	20.3	1.6	.0	8.6
Student				
Household Income Past 12 Months <$100,000	58.9	48.4	58.4	55.9

Note: [a]Some participants indicated more than one race thus the totals exceed 100%.

The PGen study included a total of 1,464 participants who engaged in DTC PGT. The sample used for this study consisted of 887, of those participants who completed the baseline, two to three week follow-up, and six month follow-up surveys. Table 4.1 offers descriptive demographic statistics for the sample included in this analysis.

Measures of Perception Motivation Theory Concepts

Perceived severity. The measure of perceived severity is an 11-item instrument with a four-option, Likert-type scale with high reliability (α=.82) and robust construct validity (Chung et al., 2009). The scale gathers information regarding the respondents' beliefs about the severity of their personal genomic testing results. These questions are included in the six-month follow-up questionnaire, a higher score on this scale indicates a higher perceived severity of the DTC PGT results.

Perceived vulnerability. The measure of perceived vulnerability is composed of nine items with a five option Likert-type scale that gathers information about respondents' perceived risk of having a genetic-linked disease. These items do not relate to the actual results from the testing company and are solely based on the respondents' beliefs about their own vulnerability to genetic disease. These questions are included in the six month follow-up questionnaire. A higher value indicates a higher perception of vulnerability to having a genetic-linked disease.

Response efficacy. A five option Likert-type single item is used to measure response efficacy in respondents (Wade et al., 2012). The item is included in the six month follow-up questionnaire. A higher score on this item indicates a stronger belief that the DTC PGT results would be helpful in improving health or avoiding illness.

Self-efficacy. The measurement for self-efficacy in respondents is a five item seven point Likert-type scale (Parrott, Silk, & Condit, 2003). The scale has a high reliability (α=.86) (McBride et al., 2009). This scale is included in the six-month follow-up questionnaire. Those respondents with a higher score on this scale believe that they

are more able to accurately engage with their genomic results and understand the results' meanings on their own.

Post Result Receipt Behaviors. The four outcome variables: 1) discussing DTC PGT results with someone else, 2) making a change in their insurance coverage in response to the DTC PGT results, 3) making a change in their retirement or financial plans in response to DTC PGT results, and 4) making a change in their advance planning as a response to their DTC PGT results are all single items. They are asked using yes or no answer choices on the six month follow up survey.

Statistical Analysis

Descriptive statistics were calculated for each of the analyzed items and contingency tables were constructed for each of the four post result receipt behaviors by each of the PMT concepts. Due to low cell counts in all of the contingency tables chi-square analyses were inappropriate. All analyses were run using IBM SPSS Statistics 23.0.

Results

Descriptive Statistics

The self-reported percentages of use of the PGT results are displayed in Table 4.2 along with the PMT conceptual measure averages included in the analysis.

Table 4.2
Personal Genomic Testing Result Usage and Protection Motivation Theory Concept Descriptive Statistics by Age Group

	19-39 years	40-59 years	60+ years	Overall
Intended to discuss results[a]	96.0 (336)	94.0 (296)	97.8 (218)	95.7 (850)
Discussed results[a]	96.6 (338)	93.0 (293)	94.6 (211)	94.8 (842)
Changed insurance coverage[a]	0.3 (1)	0.3 (1)	1.3 (3)	0.6 (5)
Changed financial/retirement[a]	0.6 (2)	2.2 (7)	4.5 (10)	2.1 (19)
Changed advance planning[a]	1.1 (4)	2.2 (7)	8.1 (18)	3.3 (29)
Perceived Severity Scale[b]	1.85 (0.37)	1.91 (0.41)	1.86 (0.40)	1.88 (0.39)
Perceived Vulnerability Scale[b]	22.67 (5.17)	23.56 (5.21)	23.44 (6.72)	23.18 (5.62)
Response Efficacy[b]	3.23 (1.05)	3.42 (1.09)	3.22 (1.13)	3.30 (1.09)
Genetic Self-Efficacy[b]	5.63 (1.10)	5.59 (1.11)	5.35 (1.05)	5.55 (1.09)

Note. [a]Item expressed in percent (n). [b]Item expressed in mean (SD).

The distributions of the participant ratings for the four concepts of the PMT are depicted in the contingency tables organized by each of the four post result receipt behaviors among each of the age groups (Tables 4.3-4.6).

Table 4.3
Protection Motivation Theory Concept Ratings Among Age Groups by Sharing Personal Genomic Testing Results

		Response Efficacy				
		1	2	3	4	5
19-39	No	1 (8.3%)	3 (25.0%)	3 (25.0%)	5 (41.7%)	0 (0.0%)
	Yes	23 (6.8%)	56 (16.6%)	104 (30.8%)	126 (37.3%)	29 (8.6%)
	Total	24 (6.9%)	59 (16.9%)	107 (30.6%)	131 (37.4%)	29 (8.3%)
40-59	No	2 (9.1%)	4 (18.2%)	9 (40.9%)	7 (31.8%)	0 (0.0%)
	Yes	19 (6.5%)	33 (11.3%)	85 (29.0%)	107 (36.5%)	49 (16.7%)
	Total	21 (6.7%)	37 (11.7%)	94 (29.8%)	114 (36.2%)	49 (15.6%)
60+	No	3 (25.0%)	3 (25.0%)	5 (41.7%)	1 (8.3%)	0 (0.0%)
	Yes	23 (10.9%)	20 (9.5%)	68 (32.2%)	78 (37.0%)	22 (10.4%)
	Total	26 (11.7%)	23 (10.3%)	73 (32.7%)	79 (35.4%)	22 (9.9%)
Total	No	6 (13.0%)	10 (21.7%)	17 (37.0%)	13 (28.3%)	0 (0.0%)
	Yes	65 (7.7%)	109 (12.9%)	257 (30.5%)	311 (36.9%)	100 (11.9%)
	Total	71 (8.0%)	119 (13.4%)	274 (30.9%)	324 (36.5%)	100 (11.3%)

Table 4.3 continued

Protection Motivation Theory Concept Ratings Among Age Groups by Sharing Personal Genomic Testing Results

		Self-Efficacy Rating				
		1	2	3	4	5
19-39	No	0 (0.0%)	0 (0.0%)	1 (8.3%)	6 (50.0%)	5 (41.7%)
	Yes	4 (1.2%)	8 (2.4%)	32 (9.5%)	97 (28.7%)	197 (58.3%)
	Total	4 (1.1%)	8 (2.3%)	33 (9.4%)	103 (29.4%)	202 (57.7%)
40-59	No	1 (4.5%)	2 (9.1%)	2 (9.1%)	8 (36.4%)	9 (40.9%)
	Yes	5 (1.7%)	3 (1.0%)	20 (6.8%)	109 (37.2%)	156 (53.2%)
	Total	6 (1.9%)	5 (1.6%)	22 (7.0%)	117 (37.1%)	165 (52.4%)
60+	No	1 (8.3%)	1 (8.3%)	4 (33.3%)	3 (25.0%)	3 (25.0%)
	Yes	3 (1.4%)	3 (1.4%)	23 (10.9%)	88 (41.7%)	94 (44.5%)
	Total	4 (1.8%)	4 (1.8%)	27 (12.1%)	91 (40.8%)	97 (43.5%)
Total	No	2 (4.3%)	3 (6.5%)	7 (15.2%)	17 (37.0%)	17 (37.0%)
	Yes	12 (1.4%)	14 (1.7%)	75 (8.9%)	294 (34.9%)	447 (53.1%)
	Total	14 (1.6%)	17 (1.9%)	82 (9.2%)	311 (35.0%)	464 (52.3%)

		Perceived Severity Rating		
		1	2	3
19-39	No	5 (41.7%)	6 (50.0%)	1 (8.3%)
	Yes	50 (14.8%)	266 (78.7%)	22 (6.5%)
	Total	55 (15.7%)	272 (77.7%)	23 (6.6%)
40-59	No	4 (18.2%)	14 (63.6%)	4 (18.2%)
	Yes	47 (16.0%)	222 (75.8%)	24 (8.2%)
	Total	51 (16.2%)	236 (74.9%)	28 (8.9%)
60+	No	3 (25.0%)	7 (58.3%)	2 (16.7%)
	Yes	36 (17.1%)	158 (74.9%)	17 (8.1%)
	Total	39 (17.5%)	165 (74.0%)	19 (8.5%)
Total	No	12 (26.1%)	27 (58.7%)	7 (15.2%)
	Yes	133 (15.8%)	646 (76.7%)	63 (7.5%)
	Total	145 (16.3%)	673 (75.8%)	70 (7.9%)

Table 4.3 continued

Protection Motivation Theory Concept Ratings Among Age Groups by Sharing Personal Genomic Testing Results

		Perceived Vulnerability Rating				
		1	2	3	4	5
19-39	No	0 (0.0%)	3 (25.0%)	7 (58.3%)	2(16.7%)	0 (0.0%)
	Yes	5 (1.5%)	30 (8.9%)	165 (48.8%)	128 (37.9%)	10 (3.0%)
	Total	5 (1.4%)	33 (9.4%)	172 (49.1%)	130 (37.1%)	10 (2.9%)
40-59	No	0 (0.0%)	3 (13.6%)	11 (50.0%)	6 (7.3%)	2 (9.1%)
	Yes	2 (.7%)	26 (8.9%)	133 (45.5%)	122 (41.8%)	9 (3.1%)
	Total	2 (.6%)	29 (9.2%)	144 (45.9%)	128 (40.8%)	11 (3.5%)
60+	No	0 (0.0%)	3 (25.0%)	6 (50.0%)	2 (16.7%)	1 (8.3%)
	Yes	0 (0.0%)	30 (14.2%)	94 (44.5%)	70 (33.2%)	17 (8.1%)
	Total	0 (0.0%)	33 (14.8%)	100 (44.8%)	72 (32.3%)	18 (8.1%)
Total	No	0 (0.0%)	9 (19.6%)	24 (52.2%)	10 (21.7%)	3 (6.5%)
	Yes	7 (.8%)	86 (10.2%)	392 (46.6%)	320 (38.0%)	36 (4.3%)
	Total	7 (.8%)	95 (10.7%)	416 (46.9%)	330 (37.2%)	39 (4.4%)

Table 4.4

Protection Motivation Theory Concept Ratings Among Age Groups by Making Changes to Health Insurance

		Response Efficacy				
		1	2	3	4	5
19-39	No	24 (6.9%)	59 (16.9%)	106 (30.4%)	131 (37.5%)	29 (8.3%)
	Yes	0 (0.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total	24 (6.9%)	59 (16.9%)	107 (30.6%)	131 (37.4%)	29 (8.3%)
40-59	No	21 (6.7%)	37 (11.8%)	94 (29.9%)	114 (36.3%)	48 (15.3%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)
	Total	21 (6.7%)	37 (11.7%)	94 (29.8%)	114 (36.2%)	49 (15.6%)
60+	No	26 (11.8%)	22 (10.0%)	73 (33.2%)	79 (35.9%)	20 (9.1%)
	Yes	0 (0.0%)	1 (33.3%)	0 (0.0%)	0 (0.0%)	2 (66.7%)
	Total	26 (11.7%)	23 (10.3%)	73 (32.7%)	79 (35.4%)	22 (9.9%)
Total	No	71 (8.0%)	118 (13.4%)	273 (30.9%)	324 (36.7%)	97 (11.0%)
	Yes	0 (0.0%)	1 (20.0%)	1 (20.0%)	0 (0.0%)	3 (60.0%)
	Total	71 (8.0%)	119 (13.4%)	274 (30.9%)	324 (36.5%)	100 (11.3%)
		Self-Efficacy Rating				
		1	2	3	4	5
19-39	No	4 (1.1%)	8 (2.3%)	33 (9.5%)	102 (29.2%)	202 (57.9%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)
	Total	4 (1.1%)	8 (2.3%)	33 (9.4%)	103 (29.4%)	202 (57.7%)
40-59	No	6 (1.9%)	5 (1.6%)	22 (7.0%)	116 (36.9%)	165 (52.5%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)
	Total	6 (1.9%)	5 (1.6%)	22 (7.0%)	117 (37.1%)	165 (52.4%)
60+	No	4 (1.8%)	4 (1.8%)	26 (11.8%)	91 (41.4%)	95 (43.2%)
	Yes	0 (0.0%)	0 (0.0%)	1 (33.3%)	0 (0.0%)	2 (66.7%)
	Total	4 (1.8%)	4 (1.8%)	27 (12.1%)	91 (40.8%)	97 (43.5%)
Total	No	14 (1.6%)	17 (1.9%)	81 (9.2%)	309 (35.0%)	462 (52.3%)
	Yes	0 (0.0%)	0 (0.0%)	1 (20.0%)	2 (40.0%)	2 (40.0%)
	Total	14 (1.6%)	17 (1.9%)	82 (9.2%)	311 (35.0%)	464 (52.3%)

Table 4.4 continued

Protection Motivation Theory Concept Ratings Among Age Groups by Making Changes to Health Insurance

		Perceived Severity Rating		
		1	2	3
19-39	No	55 (15.8%)	271 (77.7%)	23 (6.6%)
	Yes	0 (0.0%)	1 (100.0%)	0 (0.0%)
	Total	55 (15.7%)	272 (77.7%)	23 (6.6%
40-59	No	51 (16.2%)	235 (74.8%)	28 (8.9%)
	Yes	0 (0.0%)	1 (100.0%)	0 (0.0%)
	Total	51 (16.2%)	236 (74.9%)	28 (8.9%)
60+	No	39 (17.7%)	163 (74.1%)	18 (8.2%)
	Yes	0 (0.0%)	2 (66.7%)	1 (33.3%)
	Total	39 (17.5%)	165 (74.0%	19 (8.5%)
Total	No	145 (16.4%)	669 (75.8%)	69 (7.8%)
	Yes	0 (0.0%)	4 (80.0%)	1 (20.0%)
	Total	145 (16.3%)	673 (75.8%)	70 (7.9%)

		Perceived Vulnerability Rating				
		1	2	3	4	5
19-39	No	5 (1.4%)	33 (9.5%)	171 (49.0%)	130 (37.2%)	10 (2.9%)
	Yes	0 (0.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total	5 (1.4%)	33 (9.4%)	172 (49.1%)	130 (37.1%)	10 (2.9%)
40-59	No	2 (.6%)	29 (9.3%)	143 (45.7%)	128 (40.9%)	11 (3.5%)
	Yes	0 (0.0%)	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)
	Total	2 (.6%)	29 (9.2%)	144 (45.9%)	128 (40.8%)	11 (3.5%)
60+	No	0 (0.0%)	32 (14.5%)	99 (45.0%)	71 (32.3%)	18 (8.2%)
	Yes	0 (0.0%)	1 (33.3%)	1 (33.3%)	1 (33.3%)	0 (0.0%)
	Total	0 (0.0%)	33 (14.8%)	100 (44.8%)	72 (32.3%)	18 (8.1%)
Total	No	7 (.8%)	94 (10.7%)	413 (46.8%)	329 (37.3%)	39 (4.4%)
	Yes	0 (0.0%)	1 (20.0%)	3 (60.0%)	1 (20.0%)	0 (0.0%)
	Total	7 (.8%)	95 (10.7%)	416 (46.9%)	330 (37.2%)	39 (4.4%)

Table 4.5

Protection Motivation Theory Concept Ratings Among Age Groups by Making Changes to Retirement/Finances

		Response Efficacy				
		1	2	3	4	5
19-39	No	24 (6.9%)	59 (17.0%)	105 (30.2%)	131 (37.6%)	29 (8.3%)
	Yes	0 (0.0%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)
	Total	24 (6.9%)	59 (16.9%)	107 (30.6%)	131 (37.4%)	29 (8.3%)
40-59	No	21 (6.8%)	36 (11.7%)	92 (29.9%)	110 (35.7%)	49 (15.9%)
	Yes	0 (0.0%)	1 (14.3%)	2 (28.6%)	4 (57.1%)	0 (0.0%)
	Total	21 (6.7%)	37 (11.7%)	94 (29.8%)	114 (36.2%)	49 (15.6%)
60+	No	26 (12.2%)	23 (10.8%)	72 (33.8%)	71 (33.3%)	21 (9.9%)
	Yes	0 (0.0%)	0 (0.0%)	1 (10.0%)	8 (80.0%)	1 (10.0%)
	Total	26 (11.7%)	23 (10.3%)	73 (32.7%)	79 (35.4%)	22 (9.9%)
Total	No	71 (8.2%)	118 (13.6%)	269 (31.0%)	312 (35.9%)	99 (11.4%)
	Yes	0 (0.0%)	1 (5.3%)	5 (26.3%)	12 (63.2%)	1 (5.3%)
	Total	71 (8.0%)	119 (13.4%)	274 (30.9%)	324 (36.5%)	100 (11.3%)
		Self-Efficacy Rating				
		1	2	3	4	5
19-39	No	4 (1.1%)	8 (2.3%)	32 (9.2%)	102 (29.3%)	202 (58.0%)
	Yes	0 (0.0%)	0 (0.0%)	1 (50.0%)	1 (50.0%)	0 (0.0%)
	Total	4 (1.1%)	8 (2.3%)	33 (9.4%)	103 (29.4%)	202 (57.7%)
40-59	No	6 (1.9%)	4 (1.3%)	22 (7.1%)	116 (37.7%)	160 (51.9%)
	Yes	0 (0.0%)	1 (14.3%)	0 (0.0%)	1 (14.3%)	5 (71.4%)
	Total	6 (1.9%)	5 (1.6%)	22 (7.0%)	117 (37.1%)	165 (52.4%)
60+	No	4 (1.9%)	4 (1.9%)	27 (12.7%)	86 (40.4%)	92 (43.2%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (50.0%)	5 (50.0%)
	Total	4 (1.8%)	4 (1.8%)	27 (12.1%)	91 (40.8%)	97 (43.5%)
Total	No	14 (1.6%)	16 (1.8%)	81 (9.3%)	304 (35.0%)	454 (52.2%)
	Yes	0 (0.0%)	1 (5.3%)	1 (5.3%)	7 (36.8%)	10 (52.6%)
	Total	14 (1.6%)	17 (1.9%)	82 (9.2%)	311 (35.0%)	464 (52.3%)

Table 4.5 continued

Protection Motivation Theory Concept Ratings Among Age Groups by Making Changes to Retirement/Finances

		Perceived Severity Rating		
		1	2	3
19-39	No	55 (15.8%)	270 (77.6%)	23 (6.6%)
	Yes	0 (0.0%)	2 (100.0%)	0 (0.0%)
	Total	55 (15.7%)	272 (77.7%)	23 (6.6%)
40-59	No	50 (16.2%)	232 (75.3%)	26 (8.4%)
	Yes	1 (14.3%)	4 (57.1%)	2 (28.6%)
	Total	51 (16.2%)	236 (74.9%)	28 (8.9%)
60+	No	37 (17.4%)	158 (74.2%)	18 (8.5%)
	Yes	2 (20.0%)	7 (70.0%)	1 (10.0%)
	Total	39 (17.5%)	165 (74.0%)	19 (8.5%)
Total	No	142 (16.3%)	660 (75.9%)	67 (7.7%)
	Yes	3 (15.8%)	13 (68.4%)	3 (15.8%)
	Total	145 (16.3%)	673 (75.8%)	70 (7.9%)

		Perceived Vulnerability Rating				
		1	2	3	4	5
19-39	No	5 (1.4%)	33 (9.5%)	171 (49.1%)	129 (37.1%)	10 (2.9%)
	Yes	0 (0.0%)	0 (0.0%)	1 (50.0%)	1 (50.0%)	0 (0.0%)
	Total	5 (1.4%)	33 (9.4%)	172 (49.1%)	130 (37.1%)	10 (2.9%)
40-59	No	2 (.7%)	28 (9.1%)	144 (46.9%)	124 (40.4%)	9 (2.9%)
	Yes	0 (0.0%)	1 (14.3%)	0 (0.0%)	4 (57.1%)	2 (28.6%)
	Total	2 (.6%)	29 (9.2%)	144 (45.9%)	128 (40.8%)	11 (3.5%)
60+	No	0 (0.0%)	31 (14.6%)	96 (45.1%)	71 (33.3%)	15 (7.0%)
	Yes	0 (0.0%)	2 (20.0%)	4 (40.0%)	1 (10.0%)	3 (30.0%)
	Total	0 (0.0%)	33 (14.8%)	100 (44.8%)	72 (32.3%)	18 (8.1%)
Total	No	7 (.8%)	92 (10.6%)	411 (47.4%)	324 (37.3%)	34 (3.9%)
	Yes	0 (0.0%)	3 (15.8%)	5 (26.3%)	6 (31.6%)	5 (26.3%)
	Total	7 (.8%)	95 (10.7%)	416 (46.9%)	330 (37.2%)	39 (4.4%)

Table 4.6

Protection Motivation Theory Concept Ratings Among Age Groups by Making Changes to Advance Planning

		Response Efficacy				
		1	2	3	4	5
19-39	No	24 (6.9%)	59 (17.1%)	107 (30.9%)	129 (37.3%)	27 (7.8%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (50.0%)	2 (50.0%)
	Total	24 (6.9%)	59 (16.9%)	107 (30.6%)	131 (37.4%)	29 (8.3%)
40-59	No	21(6.8%)	37 (12.0%)	94 (30.5%)	111 (36.0%)	45 (14.6%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (42.9%)	4 (57.1%)
	Total	21 (6.7%)	37 (11.7%)	94 (29.8%)	114 (36.2%)	49 (15.6%)
60+	No	26 (12.7%)	22 (10.7%)	69 (33.7%)	68 (33.2%)	20 (9.8%)
	Yes	0 (0.0%)	1 (5.6%)	4 (22.2%)	11 (61.1%)	2 (11.1%)
	Total	26 (11.7%)	23 (10.3%)	73 (32.7%)	79 (35.4%)	22 (9.9%)
Total	No	71 (8.3%)	118 (13.7%)	270 (31.4%)	308 (35.9%)	92 (10.7%)
	Yes	0 (0.0%)	1 (3.4%)	4 (13.8%)	16 (55.2%)	8 (27.6%)
	Total	71 (8.0%)	119 (13.4%)	274 (30.9%)	324 (36.5%)	100 (11.3%)
		Self-Efficacy Rating				
		1	2	3	4	5
19-39	No	4 (1.2%)	8 (2.3%)	33 (9.5%)	101 (29.2%)	200 (57.8%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (50.0%)	2 (50.0%)
	Total	4 (1.1%)	8 (2.3%)	33 (9.4%)	103 (29.4%)	202 (57.7%)
40-59	No	6 (1.9%)	5 (1.6%)	22 (7.1%)	115 (37.3%)	160 (51.9%)
	Yes	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (28.6%)	5 (71.4%)
	Total	6 (1.9%)	5 (1.6%)	22 (7.0%)	117 (37.1%)	165 (52.4%)
60+	No	4 (2.0%)	4 (2.0%)	23 (11.2%)	84 (41.0%)	90 (43.9%)
	Yes	0 (0.0%)	0 (0.0%)	4 (22.2%)	7 (38.9%)	7 (38.9%)
	Total	4 (1.8%)	4 (1.8%)	27 (12.1%)	91 (40.8%)	97 (43.5%)
Total	No	14 (1.6%)	17 (2.0%)	78 (9.1%)	300 (34.9%)	450 (52.4%)
	Yes	0 (0.0%)	0 (0.0%)	4 (13.8%)	11 (37.9%)	14 (48.3%)
	Total	14 (1.6%)	17 (1.9%)	82 (9.2%)	311 (35.0%)	464 (52.3%)

Table 4.6 continued

Protection Motivation Theory Concept Ratings Among Age Groups by Making Changes to Advance Planning

		Perceived Severity Rating		
		1	2	3
19-39	No	55 (15.9%)	268 (77.5%)	23 (6.6%)
	Yes	0 (0.0%)	4 (100.0%)	0 (0.0%)
	Total	55(15.7%)	272 (77.7%)	23 (6.6%)
40-59	No	50 (16.2%)	234 (76.0%)	24 (7.8%)
	Yes	1 (14.3%)	2 (28.6%)	4 (57.1%)
	Total	51 (16.2%)	236 (74.9%)	28 (8.9%)
60+	No	37 (18.0%)	151 (73.7%)	17 (8.3%)
	Yes	2 (11.1%)	14 (77.8%)	2 (11.1%)
	Total	39 (17.5%)	165 (74.0%)	19 (8.5%)
Total	No	142 (16.5%)	653 (76.0%)	64 (7.5%)
	Yes	3 (10.3%)	20 (69.0%)	6 (20.7%)
	Total	145 (16.3%)	673 (75.8%)	70 (7.9%)

		Perceived Vulnerability Rating				
		1	2	3	4	5
19-39	No	5 (1.4%)	32 (9.2%)	171 (49.4%)	128 (37.0%)	10 (2.9%)
	Yes	0 (0.0%)	1 (25.0%)	1 (25.0%)	2 (50.0%)	0 (0.0%)
	Total	5 (1.4%)	33 (9.4%)	172 (49.1%)	130 (37.1%)	10 (2.9%)
40-59	No	2 (.7%)	28 (9.1%)	142 (46.3%)	125 (40.7%)	10 (3.3%)
	Yes	0 (0.0%)	1 (14.3%)	2 (28.6%)	3 (42.9%)	1 (14.3%)
	Total	2 (.6%)	29 (9.2%)	144 (45.9%)	128 (40.8%)	11 (3.5%)
60+	No	0 (0.0%)	33 (16.1%)	91 (44.4%)	68 (33.2%)	13 (6.3%)
	Yes	0 (0.0%)	0 (0.0%)	9 (50.0%)	4 (22.2%)	5 (27.8%)
	Total	0 (0.0%)	33 (14.8%)	100 (44.8%)	72 (32.3%)	18 (8.1%)
Total	No	7 (.8%)	93 (10.8%)	404 (47.1%)	321 (37.4%)	33 (3.8%)
	Yes	0 (0.0%)	2 (6.9%)	12 (41.4%)	9 (31.0%)	6 (20.7%)
	Total	7 (.8%)	95 (10.7%)	416 (46.9%)	330 (37.2%)	39 (4.4%)

Discussion

The analyses conducted sought to better understand several interpersonal and economic behaviors of people following the receipt of DTC PGT results. We were able to use age groups and the concepts of the PMT to analyze the respondents' decisions to

disclose their testing results to others, change health insurance, change financial and retirement plans, and change advance planning behaviors. The small size of those participants who engaged in the behaviors of interest limited the use of statistical analysis methods, and thus there are no statements of statistical significance among the contingency tables (Tables 4.3-4.6). Analyses of these numbers instead focuses on the ratings of the four PMT concept measures as they differ among the age groups and the differences between those who did and did not engage in the behavior.

These measures of the PMT concepts show some of the trends that are associated with taking or not taking the actions of interest and are important for the future of DTC PGT in the context of society and healthcare. As genomic level knowledge permeates society, more people will be armed with a large amount of information that may lead them to engage in any of these actions. Understanding these trends helps to better understand the influence that participant perceptions of self-efficacy, response efficacy, risk, and vulnerability have over these four results utilization behaviors.

In examining the sharing of DTC PGT results with another person, those who did share tended to have higher self-efficacy and response efficacy ratings. A majority of those who shared their DTC PGT results had moderate perceived severity ratings and moderate to higher perceived vulnerability ratings. When examining trends among the age groups the patterns of ratings among those who did share their results mirror the overall patterns. Greater than 80% of those who shared had high self-efficacy ratings in each of the three age groups and in the overall sample. The perceived vulnerability

ratings were higher among the 60+ group who shared their results than those who shared in the other two age groups.

More people did share their results from the DTC PGT than those who did not, this may suggest that they are seeking out the opinions of others (eg, family members, healthcare providers) regarding their results. In light of the increased perceived vulnerability scores, the opinions sought could range from seeking other's views on DTC PGT in general to dealing with specific results and many other possible perspectives of the results (McBride et al., 2010).

In examining the use of the DTC PGT results to make changes in insurance, a very low number of events prohibits making strong statements about these participants, though broadly across all age groups it is evident that moderate perceived severity and perceived vulnerability along with higher response efficacy and self-efficacy ratings were more common among those who did make changes to their insurance in response to receiving their DTC PGT results.

Those who made changes to their retirement and financial plans in response to receiving DTC PGT results were more likely to have moderate to higher response efficacy ratings, higher self-efficacy ratings, moderate perceived severity, and moderate to higher perceived vulnerability ratings. Across the age groups these were very similar, though the 19-39 group members who made changes were likely to have more moderate self-efficacy and response efficacy results than the other two age groups.

The overall trends of those who made changes to their advance directives are the same as those who made changes to retirement and financial plans. In both cases, the

majority of those participants who made changes were members of the 60+ group, though much more in the retirement changes than any other behavior. Those in the 60+ group who made changes to their retirement were more likely to have moderate to higher response efficacy ratings compared to the other two age groups where those who changed had high response efficacy ratings.

In the application of the PMT, Rogers (1983) identifies perceived vulnerability and perceived severity as contributing to the fear appeal that contributes to the drive to make changes in behavior. The findings related to these two significant measures in the four tables both support and contradict that statement. Those who had a higher perceived vulnerability are more likely to engage in the practice of sharing their DTC PGT results—the target behavior thus supporting the value of fear appeals. However, the lack of differentiation among those who did make changes to retirement by type of changes (eg. adding money, removing money, increasing deductions) makes it difficult to determine if the behaviors related to a moderate perceived severity are consistent with Rogers' thoughts about PMT (1983). The findings of this study are similar to others in noting a paradox in the perceived vulnerability and perceived severity scores and their influence on the behaviors of interest (Cismaru & Lavack, 2007). The fear of negative consequences can only be examined through the lens of the participant's evaluation of the severity of the consequences (Rogers, 1983).

Age group differences in engagement in the target behaviors may be related to situational aspects of the age groups. The 60+ group made up the largest portion of those who made changes in advance directives in response to their DTC PGT results,

which may speak to a perception among this age group of increased proximity of age-related decline or later-life disease processes. This older age group may view their results as fatalistic and seek to be proactive in addressing the possibility of a negative outcome related to genetic disease. Research has shown that 60+ year olds are more likely to have an advance directive in place than other age groups (Rao, Anderson, Lin, Laux, 2014).

The findings of this study indicate an early indication that the PMT may be a valuable tool in the evaluation of decisions made in response to DTC PGT results, an area that had not been previously studied using PMT. Additionally, the concepts of the PMT are key as they support the importance of the DTC PGT consumers' perceptions in their processing the results delivered by the service they used (Kaufman et al., 2012; McBride et al., 2010).

Limitations

The PGen data set provides a robust study design with a large sample of participants; however, there are limitations to the use of the data in this study. The sample is not as diverse as society, and is made up of mostly white, married females. Self-selection bias is also a concern for this data set as the respondents opted into the study after initiating DTC PGT. Additionally, the non-controlled design of the PGen study cannot support any conclusions related causal relationships. The small sample of events of interest is one large limitation on the analysis, and while this analysis addresses trends in ratings among age groups in those who did engage in the target events it does not offer statistical evaluations of significance because of the limited sample size. The findings in this article are specifically about DTC PGT participants' behaviors, but they

may offer some insight into trends that may also be present in clinical genetic testing populations. Further examination of the PMT as a model for the evaluation and study of DTC PGT results utilization behaviors and determining whether these trends exist outside of the study sample will require further studies in more diverse populations.

Conclusions

The relationships among age, the PMT concepts, and insurance, financial, retirement, advance directive and results disclosure behaviors of DTC PGT participants are multifaceted. Evaluation of the concepts in the PMT appears to aid in better understanding the actions that DTC PGT consumers take in response to their results. In addition to the perceptions included in the PMT concepts, the influence of age group membership must also be acknowledged as a difference in those who engaged in retirement and advance planning change behaviors; further study would be valuable in offering a deeper assessment of these age group differences. Also, further study will be valuable to evaluate the PMT concepts in genetic decision-making outside of the DTC PGT context. Subsequent studies—quantitative and qualitative—are needed to help better understand how DTC PGT companies and healthcare providers can best support the educational and decision-making needs of all those who engage in DTC PGT. A larger study with a larger sample of DTC PGT result utilization behavior events is key in understanding the role of the PMT in explaining these behaviors. In addition, there is a need to acknowledge the policy implications that these behaviors may have, while these tests are not necessarily entered into the medical record, they are influencing the consumer behaviors of the result recipients (Kaufman et al., 2012; McBride et al, 2009,

2010). Policy makers must seek to find balance in protecting commercial and consumer interests as they address the new frontiers of consumer-driven health services.

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CHAPTER FIVE

CONCLUSION

This dissertation set out to increase the state of understanding of the beliefs, knowledge, and perceptions of older adults related to genetics and genomics. Studies of decision-making related to engaging in genomic testing and utilization of the genomic testing results were conducted. In order to better describe older adults, the study compared the differences and similarities in measures over time and among three age groups, 19-39 year olds, 40-59 year olds, and 60+ year olds. The focus was on older adults in order to strengthen the current knowledge and add new findings to provide a foundation for further study to be able to move toward more individualized approaches informed by the similarities and differences of the age groups.

The three manuscripts included in this dissertation approach the area of genetic and genomic testing and decision-making from unique angles. The manuscripts attempt not only to describe the various concepts, measures, and behaviors of interest by age group but also to contextualize them within genetics and genomics. Combined, the manuscripts help to frame genetic and genomic information and decision-making across age groups to build on past studies in genetics, genomics, decision-making, and older adults.

Overview of Manuscripts

The first manuscript examines several concepts of behavioral economics, exploring the possibilities of applying the behavioral economic concepts in decision-making support related to genomics. Written as a general overview of the concepts for a

naïve audience of healthcare providers and researchers, the first manuscript provides specific situations where the concepts may be of value in clinical practice. Several concepts of behavioral economics prove to be valuable ways to explore decision-making and decision-support in the area of genomics. While these concepts have value, genomic testing and information stimulates emotions that may move beyond the realm of behavioral economic perspectives. Individual contexts are an important part of the application of behavioral economics. This manuscript is on the leading edge of genomics and behavioral economics, and this area of study shows promise for future development.

The second manuscript utilizes a secondary analysis of the Impact of Personal Genomics (PGen) data set to examine age group differences in knowledge, perspectives, and beliefs related to genetics and genomics, genetic testing and results. The article examines differences among the age groups in five specific areas: genetic knowledge, self-rated genetic competency, beliefs about personal utility of genetics, response efficacy of genetics, and influencers and reasons for engaging in direct-to-consumer personal genomic testing (DTC PGT). This article identifies several differences over time and among age groups related to these measures that provide insight into the age groups and general trends as they change over time. One overall pattern of note is that from initial evaluation to the six month follow-up evaluation the mean values for self-rated genetic competency, personal utility of genetics, and genetic response efficacy all decreased significantly, which may suggest that over time and exposure to the DTC PGT results the participants felt less confident in themselves, the testing, and the usefulness of the results. Age group differences were significant among the 60+ group in genetic knowledge and

personal utility of genetics. These may be areas where the 60+ population may benefit from increased support when engaging in genetic decision-making or genetic testing in general. Factor analysis of 19 items that evaluated participants' influences and motives for engaging in DTC PGT identified two unique factors for the overall population, 'Health and Future' and 'Curiosity and Intrigue.' Age group membership was a significant contributor to variance of mean scores of the 'Health and Future' factor with the 60+ group having a significantly lower mean score than the other two age groups. This manuscript is written with the intent to further examine differences noted among age groups in previous studies on genetic knowledge, and examine any differences in the other areas in order to build a new and better understanding of age group differences related to decision-making, genetics and genomics, and testing and results.

The third manuscript also utilizes a secondary analysis of the PGen data set as it explores the use of the Protection Motivation Theory (PMT) as a framework for better understanding reaction-behaviors of DTC PGT consumers in response to their results. The four specific reaction-behaviors of interest included: 1) disclosing of the DTC PGT results to someone else, 2) making changes to health insurance, 3) making changes to retirement and financial plans, and 4) making changes to advance planning. In addition to the concepts of the PMT, age group membership was included in the exploration of the behaviors. The findings of the study support the application of the PMT to DTC PGT consumer behaviors. Higher levels of response efficacy and self-efficacy were noted to be present in those who engaged in the studied behaviors following DTC PGT result receipt. This manuscript offers a novel area of application of the PMT in genetics and has

the possibility to inform future study and policy as the fields of genetic testing and DTC PGT continue to develop. The application of the PMT to these behaviors also supports the use of this model in further studies of decision-making in DTC PGT and clinical genetic testing populations.

Limitations and Gaps

Each of the three manuscripts has strengths and weaknesses. This dissertation includes one literature-based manuscript and two secondary data analysis-based manuscripts. The literature-based manuscript must be evaluated in light of the fact that there is currently limited research addressing the relationship between genetics and behavioral economic concepts. Genetic decision-making also has a limited research literature base. The aim of the manuscript is to examine both fields and explore the areas where overlap exists with potential as new areas for research.

While the PGen study was well designed, provided a vast amount of information about the participants, and evaluated a variety of concepts, limitations still exist. The findings in the two data-based manuscripts in this dissertation are limited in that they rely heavily on data collected by other scientists among a population that is less diverse than the general population related to a lack of diversity in ethnicity, educational attainment, and income distribution. There is inherent selection bias in the self-referral design used via the online survey service and randomization to provide a control group to strengthen comparisons was not feasible. Age grouping of the data also has limitations as there are numerous differences among age groups that may influence participation and even accuracy of the survey program. Additionally, the differences among those members in

the 60+ age group must be acknowledged as the life changes that occur after 60 years of age create a greater diversity among this age group than the age grouping may suggest. It is also important to acknowledge the very different circumstances that may surround clinical genetic testing which may not be present when the participants engaged in DTC PGT. The underlying nature of the genetic information does, however, create a common thread between DTC PGT results and clinical genetic or genomic testing.

Even with limitations, the PGen data does provide valuable initial glimpses of how individuals engage with decision-making and results utilization related to genetic-level knowledge. The dissertation work does have a few gaps, since it does not provide direct insight into the clinical genetics area. While using behavioral economics as an initial point of exploration, due to the secondary analysis design, the analysis could not be designed to test behavioral economics concepts directly. There are also some challenges in the direct translation of the behavioral economics and genetics findings into practice. There must be decision-making support and at the same time the limitation or alleviation of any perceived or actual coercion in the support provided.

In addition, the age-related differences described in this dissertation may change as generations of people with more exposure to the science of genetics and genetic testing age. This may mean that older adults may still have differences, but the knowledge-based measures may vary. Though it should be noted that as the age-knowledge difference may narrow, it is highly unlikely that the differences in genetic knowledge associated with age will be eliminated entirely as advances in genetics continue to be made. Additionally, the low number of events related to results utilization is a limitation in making any broad

generalizations to these behaviors—though it may offer important insight for the design of future research.

Discussion and Recommendations

In looking at the three manuscripts individually and as a collective work, it is apparent that the area of genetic decision-making is complex and still in the early stages of understanding. There is currently a limited foundation on which one can build a universal approach to making these decisions because of the unique nature of the genetic information that is provided through testing. The findings from these manuscripts may not be fully generalizable to the clinical testing experience; however, they do provide some insights into age group similarities and differences in trends, behaviors, and influences of genetic decision-making processes. Those insights may add to other research in the field to influence the design and implementation of clinical genetics studies or trials that address decision-making, decision aides and other interventions.

There are clear differences in the older adult population, and these differences support the need for unique approaches especially in the area of genetics. As suggested previously, the results of the second and third manuscripts have limited generalization potential. These findings need to be evaluated in more diverse populations and clinical testing situations to see if the findings are similar to those presented here.

The PMT has been applied in various aspects of genetics, but this is the first time where PMT has been applied to decision-making related to the utilization and disclosure of DTC PGT results, and genetic test results in general (Azzarello et al., 2006; Fisher et al., 2012; Helmes 2002; Ralph et al., 2014; Vadaparampil et al. 2004; Wright et al.,

2006). Additionally, the PMT constructs may be helpful in designing and testing decision-making tools and interventions to support the decision-making process.

This work has implications for practice, education, and policy, as it brings new findings and perspectives to the study of genomics and gerontology. In the realm of practice, the work of this dissertation can help increase the awareness of the context of decision-making related to healthcare and genetics (Bayliss et al, 2014; Operskalski & Barbey, 2016). Understanding that while shared decision-making and other tactics are in existence, the individual realities of the patients who are making the decisions must also be taken into account. Health care practice is moving toward an even more personalized approach as patient satisfaction and customer service become hallmarks of the industry that used to coast on "doctor knows best" paternalism (Drolet & White, 2012). In this new approach to healthcare, professionals must be informed about the range of contextual factors that influence the actions and desires of patients. In addition to the concepts of the PMT, the application of behavioral economic approaches to supporting decision-making in genetics may offer a good starting place.

As for educational implications, this work is helpful in further defining the unique needs of older adult populations specifically in genetic decision-making. Healthcare providers and researchers need to be educated about and encouraged to understand these needs and differences among age groups. The ability of the PMT to be applied in predicting behaviors after receipt of DTC PGT results further supports a need for holistic approaches to patient care. Healthcare providers should be trained to engage patients and

understand their individual perspectives and beliefs when engaging in genetic testing decision-making and discussing health behavior changes.

The growing areas of DTC PGT, clinical genetics, and genetic science in general continue to push the bounds of extant policy (McBride et al., 2010). While GINA and other policies that address genetic discrimination exist now to protect the rights of the individual to access the latest technologies available without fear of retribution, these policies will need to be revisited often in order to address new areas of concern as they develop (Green et al., 2015). The reactive behaviors of the DTC PGT participants are one example of a possible new area where policy intervention may be needed. When policies are developed to address these areas, it is imperative to protect both citizen interests and private interests. In the absence of a dual protection, provision of services may become too expensive or risky for the private entities, or access to genetic information may become too risky for citizens who may fear punitive actions from private entities based on the possibility of future disease.

Synthesis

Each of the three manuscripts approached the topic of genetics, genomics, and decision-making in a unique way, and, at the same time, the three manuscripts are complementary to each other. The behavioral economics and genomics manuscript uses an integrative review approach to evaluate the applicability of behavioral economics to genomics. As has been previously discussed, the behavioral economic approaches to decision-making do not rely solely on the emotions of decision makers (Lerner, Li, Valdesolo, & Kassam, 2015). The behavioral economic approaches to describing

decision-making behaviors also include some perspective and perception-related concepts (Ariely, 2009).

Some of the behavioral economic concepts are carried over into the second manuscript, in order to assist in contextualizing the decision-making processes. The analysis utilizes multiple measures to describe different aspects of the context of the decisions related to engaging in DTC PGT, and examines them over time. The factor analysis of the influencers and motives behind the choice to engage in DTC PGT also aids in the contextualization of the decision-making process. The evaluation of knowledge, perceptions, beliefs, and the two main factors influencing DTC PGT participation across age groups adds another layer of analysis. These three areas of analysis work in conjunction to further describe the contexts in which these decisions are made across age groups.

The third manuscript's analysis of the DTC PGT results utilization provides additional contextualization as the PMT proves to be a valuable tool in better understanding reaction-behaviors following results receipt. The four concepts of the PMT (perceived vulnerability, perceived severity, response efficacy, and self-efficacy) incorporate perspectives of the decision makers and aid in understanding some of the driving forces of the decision-making in DTC PGT consumers. The 40-59 and 60+ groups were the largest groups that made changes in insurance or finances or advance directives in response to their DTC PGT results.

The three manuscripts follow a logical progression moving from the application of the behavioral economic approaches and concepts to genomic decision-making, to the

evaluation of contextual factors as they influence DTC PGT engagement, and finally in examining the PMT, a model that incorporates some of the contextual factors, as a viable tool for studying DTC PGT results utilization. In addition to the progressive focus on context and perspective as important factors in genomic testing, these manuscripts also seek to examine the age-related differences in engagement in DTC PGT and the utilization of the results. Age is an important part of the contexts of decision-making. From a behavioral economics perspective, with increasing age the number of experiences for a person to draw on in decision-making also increases. Also, older adults may have very different perspectives and motives as a result of their advancing age. Their focus may be less future-oriented than other age groups.

Progressing from behavioral economics to the application of PMT in DTC PGT, these three manuscripts address the interface of genetics, genomics, and older adults with a specific focus on decision-making. This work further supports the limited existing literature that identifies differences in the genetic knowledge of older adults when compared to other age groups (Ashida et al. 2011; Carere et al. 2015; Morren et al, 2007). The findings in the manuscripts also build on the existing literature and expand that knowledge by examining behavioral economics as a lens for examining genomic decision-making, the context of engaging in DTC PGT, the age group differences in measures of genetic personal utility, self-rated genetic competency, and response efficacy, and PMT as a framework for studying genomic decision-making in response to DTC PGT results.

In addition to the areas where study has been expanded, several findings have the potential to shape future study. The findings from the third manuscript support the use of the PMT as a model on which to base further study of DTC PGT decision-making. As of the writing of this dissertation, PMT had never been used to study DTC PGT decision-making nor had it been applied to insurance, retirement, finance, or advance directive decision-making as a result of genetic testing. The findings related to age group differences may be useful in the design and study of personalized approaches in DTC PGT and possibly even clinical genetics. These differences could have implications for the study of decision-making, patient education, and results utilization in numerous contexts within genetics and healthcare.

This dissertation addresses a growing area of concern as genetic information is becoming a consumer-driven commodity. The field requires further exploration with this work beginning to address some key areas of the field of healthcare genetics, specifically ethics and policy as well as decision-science. The ethical and policy aspects of the work included within this dissertation span genetics and aging. There is a need for further study of the implications of genetic testing and decision-making over a broader and more diverse group of tested individuals. This work presents the study and identification of some age group differences that may be important in informing policy as the field of genetics changes. Decision-making and decision support in DTC PGT and clinical genetics are areas that continue to need support in research and practice. The understanding of the decision-making processes and contexts is an important part of ethical and professional responsibility in the use and application of genetic testing.

Decision science is also a key part of the innovation in this dissertation as it applies the PMT in new areas: DTC PGT, and making changes to health insurance, financial and retirement plans, and advance directives. The dissertation also provides further description of the different beliefs, perspectives, and knowledge related to genetics and genetic testing which are essential in the study of healthcare genetics.

Future Directions

This dissertation research has created a variety of opportunities for next steps both to build on this research and to translate the findings to inform or change practice, education, and policy. The findings identified in the three manuscripts of the dissertation will be useful in the design and implementation of studies in the clinical genetic testing environment. The designs of these studies may vary from the use of a hypothetical scenario in evaluating decision-making behavior to the use of a similar type of survey evaluating the behavioral economic, PMT, and aging concepts in a clinical genetic testing environment. Examination of the concepts in a more diverse population will also be a logical next step in expanding this work. Another area of future work is the translation of the findings into designs of novel decision support interventions or decision-making aids for clinical practice that allow for generalized support with individualization based on the patients' unique decision-making context. These different areas may be addressed individually or may be combined in several ways.

APPENDICES

APPENDIX A

DESCRIPTIVE STATISTICS FOR ALL IMPACT OF PERSONAL GENOMICS STUDY ITEMS INCLUDED IN DISSERTATION ANALYSES

Table A.1

Item-wise Analysis for Genetic Knowledge Scale by Age Group at Baseline and 6 Month Follow-up

Item (Correct Answer)	Group	Baseline	6 Month
Healthy parents can have a child with an inherited disease (T)	19-39 years old	99.1 (347)	99.7 (349)
	40-59 years old	99.7 (314)	99.0 (312)
	60+ years old	99.1 (221)	98.2 (219)
	Overall	99.3 (882)	99.1 (880)
If your close relatives have diabetes or heart disease, you are more likely to develop these conditions (T)	19-39 years old	96.3 (337)	95.7 (335)
	40-59 years old	96.5 (304)	96.2 (303)
	60+ years old	93.3 (208)	96.0 (214)
	Overall	95.6 (849)	95.9 (852)
Some genetic disorders occur more often within particular ethnic groups (T)	19-39 years old	99.4 (348)	99.4 (348)
	40-59 years old	99.0 (312)	99.4 (313)
	60+ years old	99.6 (222)	99.1 (221)
	Overall	99.3 (882)	99.3 (882)
Most genetic disorders are caused by only a single gene (F)	19-39 years old	65.4 (229)	67.1 (235)
	40-59 years old	61.9 (195)	66.7 (210)
	60+ years old	65.0 (145)	71.3 (159)
	Overall	64.1 (569)	68.0 (604)
Once a genetic marker for a disorder is identified in a person, the disorder can usually be prevented or cured (F)	19-39 years old	87.4 (306)	86.9 (304)
	40-59 years old	87.9 (277)	91.7 (289)
	60+ years old	85.2 (190)	86.1 (192)
	Overall	87.0 (773)	88.4 (785)
A disease is only genetically determined if more than one family member is affected (F)	19-39 years old	90.9 (318)	91.7 (321)
	40-59 years old	89.2 (281)	87.6 (276)
	60+ years old	84.8 (189)	82.5 (184)
	Overall	88.7 (788)	88.0 (781)
Some of the genetic disorders occur later in adult life (T)	19-39 years old	96.0 (336)	98.9 (346)
	40-59 years old	92.1 (290)	94.9 (299)
	60+ years old	91.5 (204)	90.1 (201)
	Overall	93.5 (830)	95.3 (846)
A healthy lifestyle can prevent or lessen the negative consequences of having genetic predispositions to some diseases (T)	19-39 years old	97.4 (341)	99.4 (348)
	40-59 years old	97.1 (306)	97.5 (307)
	60+ years old	92.4 (206)	96.9 (216)
	Overall	96.1 (853)	98.1 (871)
The environment has little or no effect on how genes contribute to disease (F)	19-39 years old	96.0 (336)	97.7 (342)
	40-59 years old	94.6 (298)	93.7 (295)
	60+ years old	90.1 (201)	89.2 (198)
	Overall	94.0 (835)	94.1 (835)

Note: Values represent % (n).

Table A.2

Item-wise Analysis for Self-Rated Genetic Competency Scale at Baseline Survey

Item	Group	SDA	DA	SWDA	N	SWA	A	SA	Mean(SD)
I am confident in my ability to understand information about genetics.									
	19-39 years old	2.0 (7)	0.6 (2)	3.7 (13)	3.7 (13)	12.0 (42)	34.3 (120)	43.7 (153)	6.01 (1.279)
	40-59 years old	1.9 (6)	0.3 (1)	1.0 (3)	3.2 (10)	12.4 (39)	35.6 (112)	45.7 (144)	6.13 (1.143)
	60+ years old	1.3 (3)	0.0 (0)	0.9 (2)	4.5 (10)	15.7 (35)	38.1 (85)	39.5 (88)	6.05 (1.072)
	Overall	1.8 (16)	0.3 (3)	2.0 (18)	3.7 (33)	13.1 (116)	35.7 (317	43.4 (385)	6.06 (1.182)
I am able to understand information about how genes can affect my health.									
	19-39 years old	1.7 (6)	0.0 (0)	2.3 (8)	3.1 (11)	12.9 (45)	34.3 (120)	45.7 (160)	6.11 (1.156)
	40-59 years old	1.9 (6)	0.0 (0)	1.0 (3)	2.2 (7)	10.8 (34)	38.7 (122)	45.4 (143)	6.18 (1.089)
	60+ years old	0.9 (2)	0.0 (0)	0.4 (1)	0.9 (2)	13.9 (31)	42.6 (95)	41.3 (92)	6.20 (.904)
	Overall	1.6 (14)	0.0 (0)	1.4 (12)	2.3 (20)	12.4 (110)	38.0 (337)	44.5 (395)	6.16 (1.073)
I have a good idea about how genetics may influence risk for disease generally.									
	19-39 years old	1.4 (5)	1.4 (5)	2.0 (7)	4.3 (15)	18.3 (64)	35.1 (123)	37.4 (131)	5.92 (1.221)
	40-59 years old	2.2 (7)	0.6 (2)	1.9 (6)	4.1 (13)	16.2 (51)	38.7 (122)	36.2 (114)	5.92 (1.231)
	60+ years old	0.9 (2)	1.3 (3)	0.0 (0)	4.5 (10)	18.4 (41)	44.4 (99)	30.5 (68)	5.93 (1.053)
	Overall	1.6 (14)	1.1 (10)	1.5 (13)	4.3 (38)	17.6 (156)	38.7 (344)	35.2 (313)	5.92 (1.184)
I have a good idea about how my own genetic make-up might affect my risk for disease.									
	19-39 years old	2.3 (8)	2.3 (8)	5.7 (20)	6.6 (23)	20.9 (73)	31.7 (111)	30.6 (107)	5.59 (1.437)
	40-59 years old	1.9 (6)	2.2 (7)	3.2 (10)	9.2 (29)	18.1 (57)	35.2 (111)	30.2 (95)	5.66 (1.363)
	60+ years old	0.9 (2)	2.2 (5)	1.8 (4)	7.6 (17)	18.8 (42)	43.0 (96)	25.6 (57)	5.73 (1.194)
	Overall	1.8 (16)	2.3 (20)	3.8 (34)	7.8 (69)	19.4 (172)	35.8 (318)	29.3 (259)	5.65 (1.353)
I am able to explain to others how genes affect one's health.									
	19-39 years old	2.3 (8)	3.1 (11)	6.3 (22)	8.9 (31)	25.4 (89)	28.3 (99)	25.7 (90)	5.40 (1.466)
	40-59 years old	3.5 (11)	1.3 (4)	6.0 (19)	9.8 (31)	28.3 (89)	25.4 (80)	25.7 (81)	5.37 (1.471)
	60+ years old	1.3 (3)	3.1 (7)	5.4 (12)	18.4 (41)	28.7 (64)	25.6 (57)	17.5 (39)	5.17 (1.354)
	Overall	2.5 (22)	2.5 (22)	6.0 (53)	11.6 (103)	27.3 (242)	26.6 (236)	23.6 (210)	5.33 (1.442)

Note: SDA=Strongly Disagree; DA=Disagree; SWDA= Somewhat Disagree; N=Neutral; SWA=Somewhat Agree; A=Agree; SA=Strongly Agree.

Values Represent: %(n)

Table A.3

Item-wise Analysis for Self-Rated Genetic Competency Scale at 6 Month Follow-up Survey

Item	Group	SDA	DA	SWDA	N	SWA	A	SA	Mean(SD)
I am confident in my ability to understand information about genetics.									
	19-39 years old	0.9 (3)	2.3 (8)	4.3 (15)	4.9 (17)	20.0 (70)	40.9 (143)	26.9 (94)	5.71 (1.244)
	40-59 years old	1.6 (5)	0.0 (0)	4.1 (13)	4.1 (13)	27.3 (86)	36.8 (116)	26.0 (82)	5.70 (1.176)
	60+ years old	1.3 (3)	3.6 (8)	4.5 (10)	11.2 (25)	24.2 (54)	40.4 (90)	14.8 (33)	5.34 (1.311)
	Overall	1.2 (11)	1.8 (16)	4.3 (38)	6.2 (55)	23.6 (210)	39.3 (349)	23.5 (209)	5.61 (1.247)
I am able to understand information about how genes can affect my health.									
	19-39 years old	0.9 (3)	1.4 (5)	2.3 (8)	5.1 (18)	24.0 (84)	38.6 (135)	27.7 (97)	5.77 (1.149)
	40-59 years old	1.6 (5)	0.3 (1)	2.5 (8)	3.2 (10)	28.6 (90)	36.2 (114)	27.6 (87)	5.76 (1.145)
	60+ years old	0.9 (2)	0.9 (2)	3.1 (7)	4.9 (11)	26.5 (59)	47.5 (106)	16.1 (36)	5.62 (1.066)
	Overall	1.1 (10)	0.9 (8)	2.6 (23)	4.4 (39)	26.2 (233)	40.0 (355)	24.8 (220)	5.73 (1.128)
I have a good idea about how genetics may influence risk for disease generally.									
	19-39 years old	0.9 (3)	0.6 (2)	3.1 (11)	4.0 (14)	24.0 (84)	39.7 (139)	27.7 (97)	5.80 (1.108)
	40-59 years old	1.6 (5)	0.6 (2)	1.6 (5)	5.7 (18)	26.3 (83)	39.0 (123)	25.1 (79)	5.72 (1.145)
	60+ years old	0.9 (2)	0.9 (2)	2.2 (5)	5.8 (13)	31.8 (71)	42.6 (95)	15.7 (35)	5.57 (1.050)
	Overall	1.1 (10)	0.7 (6)	2.4 (21)	5.1 (45)	26.8 (238)	40.2 (357)	23.8 (211)	5.71 (1.109)
I have a good idea about how my own genetic make-up might affect my risk for disease.									
	19-39 years old	0.9 (3)	1.1 (4)	3.4 (12)	3.4 (12)	29.7 (104)	39.1 (137)	22.3 (78)	5.67 (1.120)
	40-59 years old	1.6 (5)	1.0 (3)	1.6 (5)	3.8 (12)	29.8 (94)	39.4 (124)	22.9 (72)	5.69 (1.131)
	60+ years old	0.4 (1)	0.9 (2)	2.7 (6)	5.8 (13)	29.1 (65)	47.5 (106)	13.5 (30)	5.59 (.996)
	Overall	1.0 (9)	1.0 (9)	2.6 (23)	4.2 (37)	29.6 (263)	41.3 (367)	20.3 (180)	5.65 (1.094)
I am able to explain to others how genes affect one's health.									
	19-39 years old	1.7 (6)	4.0 (14)	7.4 (26)	9.7 (34)	30.9 (108)	25.7 (90)	20.6 (72)	5.23 (1.435)
	40-59 years old	2.9 (9)	2.5 (8)	9.2 (29)	10.2 (32)	37.1 (117)	22.2 (70)	15.9 (50)	5.06 (1.420)
	60+ years old	4.0 (9)	5.8 (13)	9.4 (21)	18.8 (42)	34.1 (76)	19.3 (43)	8.5 (19)	4.65 (1.468)
	Overall	2.7 (24)	3.9 (35)	8.6 (76)	12.2 (108)	33.9 (301)	22.9 (203)	15.9 (141)	5.03 (1.455)

Note: SDA=Strongly Disagree; DA=Disagree; SWDA= Somewhat Disagree; N=Neutral; SWA=Somewhat Agree; A=Agree; SA=Strongly Agree.

Values Represent: %(n)

Table A.4

Item-wise Analysis for Personal Utility Items at 2-3 Week Follow-up Survey

Item	Group	SDA	SWDA	N	SWA	SA	Mean (SD)
The information I received from [company] has influenced how I will manage my health in the future.							
	19-39 years old (350)	4.3 (15)	6.6 (23)	15.4 (54)	55.7 (195)	18 .0 (63)	3.77 (.965)
	40-59 years old (315)	4.1 (13)	5.7 (18)	18.1 (57)	50.8 (160)	21.3 (67)	3.79 (.977)
	60+ years old (223)	6.7 (15)	7.2 (16)	24.2 (54)	43.0 (96)	18.8 (42)	3.60 (1.081)
	Overall (888)	4.8 (43)	6.4 (57)	18.6 (165)	50.8 (451)	19.4 (172)	3.73 (1.001)
Having personal genomic testing made me feel like I have more control over my health.							
	19-39 years old (350)	2.3 (8)	4.6 (16)	15.7 (55)	47.7 (167)	29.7 (104)	3.98 (.919)
	40-59 years old (315)	4.8 (15)	4.8 (15)	16.8 (53)	46.3 (146)	27.3 (86)	3.87 (1.023)
	60+ years old (223)	8.1 (18)	8.1 (18)	18.8 (42)	38.1 (85)	26.9 (60)	3.68 (1.187)
	Overall (888)	4.6 (41)	5.5 (49)	16.9 (150)	44.8 (398)	28.2 (250)	3.86 (1.034)
Having personal genomic testing helped me to get a better perspective on my health status.							
	19-39 years old (350)	1.7 (6)	3.4 (12)	10.3 (36)	49.4 (173)	35.1 (123)	4.13 (0.855)
	40-59 years old (315)	3.2 (10)	2.5 (8)	9.5 (30)	50.2 (158)	34.6 (109)	4.10 (0.906)
	60+ years old (223)	4.5 (10)	4.5 (10)	11.7 (26)	46.2 (103)	33.2 (74)	3.99 (1.151)
	Overall (888)	2.9 (26)	3.4 (30)	10.4 (92)	48.9 (434)	34.5 (306)	4.09 (1.089)

Note: SDA=Strongly Disagree; SWDA= Somewhat Disagree; N=Neutral; SWA=Somewhat Agree; SA=Strongly Agree. Values represent %(n).

Table A.5

Item-wise Analysis for Personal Utility Items at 6 Month Follow-up Survey

Item	Group	SDA	SWDA	N	SWA	SA	Mean (SD)
The information I received from [company] has influenced how I will manage my health in the future.							
	19-39 years old (350)	6.3 (22)	8.9 (31)	23.7 (83)	45.7 (160)	15.4 (54)	3.55 (1.055)
	40-59 years old (315)	6.3 (20)	7.0 (22)	25.1 (79)	42.2 (133)	19.4 (61)	3.61 (1.72)
	60+ years old (223)	11.2 (25)	7.6 (17)	26.5 (59)	41.7 (93)	13.0 (29)	3.38 (1.151)
	Overall (888)	7.5 (67)	7.9 (70)	24.9 (221)	43.5 (386)	16.2 (144)	3.53 (1.089)
Having personal genomic testing made me feel like I have more control over my health.							
	19-39 years old (350)	4.9 (17)	9.4 (33)	18.6 (65)	48.6 (170)	18.6 (65)	3.67 (1.038)
	40-59 years old (315)	6.7 (21)	6.0 (19)	19.o (60)	44.8 (141)	23.5 (74)	3.72 (1.093)
	60+ years old (223)	9.9 (22)	6.3 (14)	22.0 (49)	40.8 (91)	21.1 (47)	3.57 (1.179)
	Overall (888)	6.8 (60)	7.4 (66)	19.6 (174)	45.3 (402)	20.9 (186)	3.66 (1.095)
Having personal genomic testing helped me to get a better perspective on my health status.							
	19-39 years old (350)	3.1 (11)	6.6 (23)	14.9 (52)	52.0 (182)	23.4 (82)	3.86 (.955)
	40-59 years old (315)	3.8 (12)	4.8 (15)	12.8 (40)	48.9 (154)	29.8 (94)	3.96 (.980)
	60+ years old (223)	7.2 (16)	4.5 (10)	16.6 (37)	43.9 (98)	27.8 (62)	3.81 (1.112)
	Overall (888)	4.4 (39)	5.4 (48)	14.5 (129)	48.9 (434)	26.8 (238)	3.88 (1.006)

Note: SDA=Strongly Disagree; SWDA= Somewhat Disagree; N=Neutral; SWA=Somewhat Agree; SA=Strongly Agree. Values represent %(n).

Table A.6

Response Efficacy Item at Baseline and 6 Month Follow-up Surveys

	Group	SDA	SWDA	N	SWA	A	Mean (SD)
What I learned from my personal genomic testing can help reduce my chances of getting sick.							
Baseline	19-39 years old (350)	3.1 (11)	15.3 (54)	20.9 (73)	50.6 (177)	10.0 (35)	3.49 (.975)
	40-59 years old (315)	3.8 (12)	13.0 (41)	29.8 (94)	43.2 (136)	10.2 (32)	3.43 (.970)
	60+ years old (223)	4.5 (10)	9.9 (22)	39.5 (88)	36.8 (82)	9.4 (21)	3.37 (.944)
	Overall (888)	3.7 (33)	13.2 (117)	28.7 (255)	44.5 (395)	9.9 (88)	3.44 (.965)
6 Month Follow-up	19-39 years old (350)	6.9 (24)	16.9 (59)	30.6 (107)	37.4 (131)	8.3 (29)	3.23 (1.047)
	40-59 years old (315)	6.7 (21)	11.7 (37)	29.8 (94)	36.2 (114)	15.6 (49)	3.42 (1.093)
	60+ years old (223)	11.7 (26)	10.3 (23)	32.7 (73)	35.4 (79)	9.9 (22)	3.22 (1.130)
	Overall (888)	8.0 (71)	13.4 (119)	30.9 (274)	36.5 (324)	11.3 (100)	3.30 (1.088)

Note: SDA=Strongly Disagree; SWDA= Somewhat Disagree; N=Neutral; SWA=Somewhat Agree; SA=Strongly Agree. Values represent %(n).

Table A.7

Item-wise Analysis of Importance of Reasons to Test

Group	NI	SWI	VI	Mean (SD)
Curiosity about my genetic make up				
19-39 years old	1.7 (6)	20.6 (72)	77.7 (272)	2.76 (.466)
40-59 years old	1.6 (5)	21.0 (66)	77.5 (244)	2.76 (.464)
60+ years old	0.4 (1)	17.0 (38)	82.5 (184)	2.82 (.396)
Overall	1.4 (12)	19.8 (176)	78.8 (700)	2.77 (.449)
Interest in finding out about my personal risk for specific diseases				
19-39 years old	4.6 (16)	23.1 (81)	72.3 (253)	2.68 (.558)
40-59 years old	7.0 (22)	29.9 (94)	63.1 (198)	2.56 (.623)
60+ years old	11.2 (25)	38.6 (86)	50.2 (112)	2.39 (.681)
Overall	7.1 (63)	29.4 (261)	63.5 (563)	2.56 (.623)
Desire to learn about my genetic makeup without going through a physician				
19-39 years old	34.6 (121)	34.0 (119)	31.4 (110)	1.97 (.813)
40-59 years old	38.7 (122)	30.2 (95)	32.2 (98)	1.92 (.834)
60+ years old	51.6 (115)	28.7 (64)	19.7 (44)	1.68 (.784)
Overall	40.3 (358)	31.3 (278)	28.4 (252)	1.88 (.821)
Desire to improve my health				
19-39 years old	11.4 (4)	41.4 (145)	47.1 (165)	2.36 (.678)
40-59 years old	10.8 (34)	37.9 (119)	51.3 (161)	2.40 (.677)
60+ years old	18.8 (42)	38.1 (85)	43.0 (96)	2.24 (.750)
Overall	13.1 (116)	39.3 (349)	47.6 (422)	2.34 (.699)
Interest in finding out about my individual response to different types of medications				
19-39 years old	18.3 (64)	39.7 (139)	42.0 (147)	2.24 (.740)
40-59 years old	22.3 (70)	34.7 (109)	43.0 (135)	2.21 (.782)
60+ years old	24.2 (54)	35.0 (78)	40.8 (91)	2.17 (.791)
Overall	21.2 (188)	36.8 (326)	42.1 (373)	2.21 (.768)
Desire to create a better plan for the future				
19-39 years old	12.9 (45)	38.3 (134)	48.9 (171)	2.36 (.699)
40-59 years old	17.8 (56)	34.1 (107)	48.1 (151)	2.30 (.755)
60+ years old	26.5 (59)	31.4 (70)	42.2 (94)	2.16 (.815)
Overall	18.0 (160)	35.1 (311)	46.9 (416)	2.29 (.753)
Personal interest in genetics in general				
19-39 years old	6.9 (24)	36.6 (127)	56.9 (199)	2.50 (.623)
40-59 years old	5.7 (18)	39.4 (124)	54.9 (173)	2.49 (.604)
60+ years old	8.1 (18)	35.4 (79)	56.5 (126)	2.48 (.643)
Overall	6.8 (60)	37.2 (330)	56.1 (498)	2.49 (.621)
The service seemed like it would be fun and entertaining				
19-39 years old	16.6 (58)	40.6 (142)	42.9 (150)	2.26 (.726)
40-59 years old	25.8 (81)	42.7 (134)	31.5 (99)	2.06 (.756)
60+ years old	25.1 (56)	43.0 (96)	31.8 (71)	2.07 (.753)
Overall	22.0 (195)	41.9 (372)	36.1 (320)	2.14 (.749)

Table A.7 continued

Item-wise Analysis of Importance of Reasons to Test

Group	NI	SWI	VI	Mean (SD)
Other members of my family are using personal genomic services				
19-39 years old	80.0 (132)	11.4 (40)	8.6 (30)	1.29 (0.614)
40-59 years old	82.9 (261)	10.2 (32)	7.0 (22)	1.24 (0.569)
60+ years old	70.8 (158)	14.8 (33)	14.3 (32)	1.44 (0.732)
Overall	78.4 (699)	11.8 (105)	9.5 (84)	1.31 (0.634)
Desire to learn more about my genetics because I have limited information about my family health history				
19-39 years old	30.3 (106)	32.6 (114)	37.1 (130)	2.07 (0.819)
40-59 years old	32.7 (103)	35.2 (111)	32.1 (101)	1.99 (0.806)
60+ years old	23.8 (53)	38.6 (86)	37.7 (84)	2.14 (0.773)
Overall	29.5 (262)	35.0 (311)	35.5 (315)	2.06 (0.804)
Desire to learn more about my genetics because I am adopted				
19-39 years old	93.7 (328)	0.6 (2)	5.7 (20)	1.12 (0.470)
40-59 years old	91.1 (287)	2.5 (8)	6.3 (20)	1.15 (0.507)
60+ years old	96.4 (215)	0.9 (2)	2.7 (6)	1.06 (0.336)
Overall	93.5 (830)	1.4 (12)	5.2 (46)	1.12 (0.455)
Interest in getting information about the risk of health conditions for my current children or future children.				
19-39 years old	21.4 (75)	27.4 (96)	51.1 (179)	2.30 (0.800)
40-59 years old	42.9 (135)	21.0 (66)	36.2 (114)	1.93 (0.888)
60+ years old	30.5 (68)	26.9 (60)	42.6 (95)	2.21 (0.848)
Overall	31.3 (278)	25.0 (222)	43.7 (388)	2.12 (0.858)

Note: NI=Not Important, SWI=Somewhat Important, VI=Very Important.
Values represent %(n).

Table A.8

Item-wise Analysis of Consideration Given to Reasons to Test

Group	DNC	CSW	CAL	Mean (SD)
How well the results predict whether or not I'm going to get a particular disease				
19-39 years old	15.1 (53)	51.7 (181)	33.1 (116)	2.18 (.672)
40-59 years old	14.0 (44)	55.2 (174)	30.8 (97)	2.17 (.649)
60+ years old	24.2 (54)	46.6 (104)	29.1 (65)	2.05 (.730)
Overall	17.0 (151)	51.7 (459)	31.3 (278)	2.14 (.681)
Privacy of my genetic information				
19-39 years old	19.4 (68)	41.7 (146)	38.9 (136)	2.19 (.739)
40-59 years old	15.9 (50)	38.7 (122)	45.4 (143)	2.30 (.726)
60+ years old	27.4 (61)	35.0 (78)	37.7 (84)	2.10 (.802)
Overall	20.2 (179)	39.0 (346)	40.9 (363)	2.21 (.754)
Whether or not there are health-related actions I can take as a result of learning my genetic information				
19-39 years old	9.1 (32)	38.0 (133)	52.9 (185)	2.44 (.656)
40-59 years old	7.9 (25)	35.9 (113)	56.2 (177)	2.48 (.640)
60+ years old	11.7 (26)	39.9 (89)	48.4 (108)	2.37 (.684)
Overall	9.3 (83)	37.7 (335)	52.9 (470)	2.44 (.658)
The possibility that I might receive unwanted information				
19-39 years old	29.1 (102)	41.4 (145)	29.4 (103)	2.00 (.766)
40-59 years old	33.3 (105)	44.1 (139)	22.5 (71)	1.89 (.741)
60+ years old	49.8 (111)	37.7 (84)	12.6 (28)	1.63 (.698)
Overall	35.8 (318)	41.4 (368)	22.7 (202)	1.87 (.754)
Cost of services				
19-39 years old	19.4 (68)	41.7 (146)	38.9 (136)	2.19 (.739)
40-59 years old	21.0 (66)	47.0 (148)	32.1 (101)	2.11 (.721)
60+ years old	35.9 (80)	45.3 (101)	18.8 (42)	1.83 (.721)
Overall	24.1 (214)	44.5 (395)	31.4 (279)	2.07 (.742)
The education materials made available through the company				
19-39 years old	33.4 (117)	46.0 (161)	20.6 (72)	1.87 (.725)
40-59 years old	27.0 (85)	50.8 (160)	22.2 (70)	1.95 (.701)
60+ years old	26.5 (59)	47.1 (105)	26.4 (59)	2.00 (.729)
Overall	29.4 (261)	48.0 (426)	22.6 (201)	1.93 (.719)
The convenience of being tested at home				
19-39 years old	18.9 (66)	37.1 (130)	44.0 (154)	2.25 (.753)
40-59 years old	16.8 (53)	40.6 (128)	42.5 (134)	2.26 (.727)
60+ years old	14.3 (32)	35.9 (80)	49.8 (111)	2.35 (.720)
Overall	17.0 (151)	38.1 (338)	44.9 (399)	2.28 (.736)

Note: DNC=Did not consider; CSW=Considered Somewhat; CAL=Considered a lot. Values Represent % (n).

Table A.9

Perceived Severity Item-wise Analysis Measuring Frequency of Responses to Personal Genomic Testing Results

Group	Never	Rarely	Sometimes	Often	Mean (SD)
Felt upset about my results					
19-39 years old	71.7 (251)	21.7 (76)	6.0 (21)	0.6 (2)	1.35 (0.62)
40-59 years old	73.7 (232)	20.3 (64)	5.7 (18)	0.3 (1)	1.33 (0.60)
60+ years old	74.0 (165)	17.5 (39)	4.9 (11)	3.6 (8)	1.38 (0.74)
Overall	73.0 (648)	20.2 (179)	50 (5.6)	1.2 (11)	1.35 (0.64)
Felt relieved about my results[a]					
19-39 years old	15.4 (54)	17.1 (60)	47.4 (166)	20.0 (70)	2.72 (0.96)
40-59 years old	21.3 (67)	19.7 (62)	44.1 (139)	14.9 (47)	2.53 (0.99)
60+ years old	19.3 (43)	16.6 (37)	38.6 (86)	25.6 (57)	2.70 (1.05)
Overall	18.5 (164)	17.9 (159)	44.0 (391)	19.6 (174)	2.65 (1.00)
Felt happy about my results[a]					
19-39 years old	12.3 (43)	19.1 (67)	44.6 (156)	24.0 (84)	2.80 (0.94)
40-59 years old	15.2 (48)	20.3 (64)	46.7 (147)	17.8 (56)	2.67 (0.94)
60+ years old	12.1 (27)	14.8 (33)	45.7 (102)	27.4 (61)	2.88 (0.95)
Overall	13.3 (118)	18.5 (164)	45.6 (405)	22.6 (201)	2.78 (0.95)
Felt motivated to change my lifestyle because of my results					
19-39 years old	29.4 (103)	31.4 (110)	30.0 (105)	9.1 (32)	2.19 (0.96)
40-59 years old	23.8 (75)	27.6 (87)	34.9 (110)	13.7 (43)	2.38 (0.99)
60+ years old	26.5 (59)	30.9 (69)	34.1 (76)	8.5 (19)	2.25 (0.94)
Overall	26.7 (237)	30.0 (266)	32.8 (291)	10.6 (94)	2.27 (0.97)
Worried about my risk of getting diseases					
19-39 years old	36.9 (129)	44.0 (154)	18.0 (63)	1.1 (4)	1.83 (0.75)
40-59 years old	38.7 (122)	41.9 (132)	15.9 (50)	3.5 (11)	1.84 (0.81)
60+ years old	44.4 (99)	35.0 (78)	19.7 (44)	0.9 (2)	1.77 (0.79)
Overall	39.4 (350)	41.0 (364)	17.7 (157)	1.9 (17)	1.82 (0.79)

Table Continues

Table A.9 continued

Perceived Severity Item-wise Analysis Measuring Frequency of Responses to Personal Genomic Testing Results

Group	Never	Rarely	Sometimes	Often	Mean (SD)
Been uncertain about what my results mean about my risk of developing diseases					
19-39 years old	46.3 (162)	32.3 (113)	19.7 (69)	1.7 (6)	1.77 (0.82)
40-59 years old	47.3 (149)	33.7 (106)	16.2 (51)	2.9 (9)	1.75 (0.83)
60+ years old	93 (41.7)	35.0 (78)	17.5 (39)	5.8 (13)	1.87 (0.90)
Overall	45.5 (404)	33.4 (297)	17.9 (159)	3.2 (28)	1.79 (0.85)
Been uncertain about what my results mean for my child(ren)'s and/or family's disease risk					
19-39 years old	50.3 (176)	28.9 (101)	18.6 (65)	2.3 (8)	1.73 (0.84)
40-59 years old	55.9 (176)	26.3 (83)	14.6 (46)	3.2 (10)	1.65 (0.84)
60+ years old	47.1 (105)	27.4 (61)	21.5 (48)	4.0 (9)	1.83 (0.91)
Overall	51.5 (457)	27.6 (245)	17.9 (159)	3.0 (27)	1.73 (0.86)
Felt unsure about what to do to prevent diseases					
19-39 years old	55.1 (193)	31.1 (109)	11.4 (40)	2.3 (8)	1.61 (0.78)
40-59 years old	55.6 (175)	28.9 (91)	13.0 (41)	2.5 (8)	1.63 (0.81)
60+ years old	49.3 (110)	35.0 (78)	13.9 (31)	1.8 (4)	1.68 (0.78)
Overall	53.8 (478)	31.3 (278)	12.6 (112)	2.3 (20)	1.63 (0.79)
Felt concerned about how my results will affect my insurance status					
19-39 years old	73.4 (257)	15.7 (55)	9.7 (34)	1.1 (4)	1.39 (0.71)
40-59 years old	64.0 (201)	24.5 (77)	8.9 (28)	2.5 (8)	1.50 (0.76)
60+ years old	76.7 (171)	14.8 (33)	7.6 (17)	0.9 (2)	1.33 (0.66)
Overall	70.9 (629)	18.6 (165)	8.9 (79)	1.6 (14)	1.41 (0.72)
Had difficulty talking about my results with others					
19-39 years old	81.7 (286)	14.3 (50)	4.0 (14)	0.0 (0)	1.22 (0.50)
40-59 years old	72.4 (228)	21.6 (68)	3.8 (12)	2.2 (7)	1.36 (0.66)
60+ years old	77.1 (172)	14.3 (32)	5.4 (12)	3.1 (7)	1.35 (0.72)
Overall	77.3 (686)	16.9 (150)	4.3 (38)	1.6 (14)	1.30 (0.63)

Table Continues

Table A.9 continued

Perceived Severity Item-wise Analysis Measuring Frequency of Responses to Personal Genomic Testing Results

Group	Never	Rarely	Sometimes	Often	Mean (SD)
Wanted to tell others about my results[a]					
19-39 years old	12.0 (42)	18.6 (65)	46.3 (162)	23.1 (81)	2.81 (0.93)
40-59 years old	13.0 (41)	19.0 (60)	47.0 (148)	21.0 (66)	2.76 (0.93)
60+ years old	17.9 (40)	18.4 (41)	46.6 (104)	17.0 (38)	2.63 (0.97)
Overall	13.9 (123)	18.7 (166)	46.6 (414)	20.8 (185)	2.74 (0.94)

Note: Values represent % (n)

[a]These results were reverse coded for use in calculation of Perceived Severity Scale

Table A.10

Perceived Vulnerability Item-wise Analysis Measuring Perceptions of Personal Risk for Developing Health Conditions

	Groups	MLTA	LTA	A	HTA	MHTA	Already Dx	Mean (SD)
Alzheimer's	19-39 years old	8.9 (31)	34.3 (120)	38.9 (136)	14.3 (50)	3.7 (13)	0.0 (0)	2.70 (0.95)
Disease	40-59 years old	9.2 (29)	34.1 (107)	34.1 (107)	16.9 (53)	5.7 (18)	0.0 (0)	2.76 (1.03)
	60+ years old	17.5 (39)	31.8 (71)	29.6 (66)	17.5 (39)	3.6 (8)	0.0 (0)	2.58 (1.08)
	Overall	11.2 (99)	33.6 (298)	34.8 (309)	16.0 (142)	4.4 (39)	0.0 (0)	2.69 (1.01)
Breast	19-39 years old	6.0 (12)	25.1 (50)	51.3 (102)	14.6 (29)	2.5 (5)	0.5 (1)	2.85 (0.95)
Cancer[a]	40-59 years old	8.9 (18)	30.7 (62)	46.0 (93)	11.9 (24)	0.5 (1)	2.0 (4)	2.76 (1.21)
	60+ years old	12.8 (16)	27.2 (34)	41.6 (52)	12.8 (16)	2.4 (3)	3.2 (4)	2.84 (1.47)
	Overall	8.7 (46)	27.8 (146)	47.0 (247)	13.1 (69)	1.7 (9)	1.7 (9)	2.82 (1.19)
Prostate	19-39 years old	9.3 (14)	17.2 (26)	53.6 (81)	13.2 (20)	6.6 (10)	0.0 (0)	2.91 (0.97)
Cancer[a]	40-59 years old	3.6 (4)	22.3 (25)	58.0 (65)	13.4 (15)	0.9 (1)	1.8 (2)	2.96 (1.09)
	60+ years old	7.1 (7)	17.3 (17)	42.9 (42)	15.3 (15)	4.1 (4)	13.3 (13)	3.71 (2.26)
	Overall	6.9 (25)	18.8 (68)	52.1 (188)	13.9 (50)	4.2 (15)	4.2 (15)	3.14 (1.50)
Colorectal	19-39 years old	8.3 (29)	19.7 (69)	55.1 (193)	14.6 (51)	2.0 (7)	0.3 (1)	2.84 (0.91)
Cancer	40-59 years old	6.7 (21)	21.3 (67)	52.9 (166)	17.5 (55)	1.6 (5)	0.0 (0)	2.86 (0.84)
	60+ years old	7.2 (16)	34.1 (76)	40.8 (91)	14.3 (32)	3.6 (8)	0.0 (0)	2.73 (0.92)
	Overall	7.4 (66)	23.9 (212)	50.7 (450)	15.6 (138)	2.3 (20)	0.1 (1)	2.82 (0.89)
Lung Cancer	19-39 years old	13.1 (46)	24.6 (86)	49.1 (172)	10.9 (38)	2.3 (8)	0.0 (0)	2.65 (0.92)
	40-59 years old	15.0 (47)	28.7 (90)	44.6 (140)	10.5 (33)	1.0 (3)	0.3 (1)	2.56 (0.98)
	60+ years old	24.7 (55)	30.5 (68)	30.0 (67)	13.0 (29)	0.9 (2)	0.9 (2)	2.40 (1.20)
	Overall	16.7 (148)	27.5 (244)	42.7 (379)	11.3 (100)	1.5 (13)	0.3 (3)	2.55 (1.02)
Diabetes	19-39 years old	9.7 (34)	20.6 (72)	45.1 (158)	18.6 (65)	5.1 (18)	0.9 (3)	2.94 (1.14)
	40-59 years old	8.6 (27)	24.5 (77)	38.2 (120)	22.3 (70)	4.5 (14)	1.9 (6)	3.01 (1.30)
	60+ years old	13.5 (30)	25.1 (56)	34.4 (77)	14.8 (33)	4.5 (10)	7.6 (17)	3.17 (1.96)
	Overall	10.3 (91)	23.1 (205)	40.0 (355)	18.9 (168)	4.7 (42)	2.9 (26)	3.02 (1.44)

Table Continues

Table A.10 continued

Perceived Vulnerability Item-wise Analysis Measuring Perceptions of Personal Risk for Developing Health Conditions

	Groups	MLTA	LTA	A	HTA	MHTA	Already Dx	Mean (SD)
Heart	19-39 years old	7.4 (26)	18.6 (65)	40.6 (142)	26.6 (93)	6.6 (23)	0.3 (1)	3.08 (1.05)
Disease	40-59 years old	3.8 (12)	14.6 (46)	42.4 (133)	33.1 (104)	5.7 (18)	0.3 (1)	3.24 (0.96)
	60+ years old	5.4 (12)	22.4 (50)	35.4 (79)	24.2 (54)	5.4 (12)	7.2 (16)	3.45 (1.82)
	Overall	5.6 (50)	18.2 (161)	39.9 (354)	28.3 (251)	6.0 (53)	2.0 (18)	3.23 (1.27)
Obesity	19-39 years old	15.7 (55)	21.4 (75)	38.9 (136)	16.3 (57)	2.6 (9)	5.1 (18)	2.99 (1.72)
	40-59 years old	10.5 (33)	14.6 (46)	36.9 (116)	22.6 (71)	3.2 (10)	12.1 (38)	3.66 (2.20)
	60+ years old	17.0 (38)	17.9 (40)	30.5 (68)	21.5 (48)	3.6 (8)	9.4 (21)	3.33 (2.13)
	Overall	14.2 (126)	18.2 (161)	36.1 (320)	19.8 (176)	3.0 (27)	8.7 (77)	3.31 (2.03)
Parkinson's	19-39 years old	11.7 (41)	27.1 (95)	51.1 (179)	9.7 (34)	0.3 (1)	0.0 (0)	2.60 (0.83)
Disease	40-59 years old	10.8 (34)	32.2 (101)	46.2 (145)	7.3 (23)	2.5 (8)	1.0 (3)	2.64 (1.07)
	60+ years old	16.6 (37)	39.0 (87)	32.7 (73)	7.2 (16)	1.8 (4)	2.7 (6)	2.55 (1.40)
	Overall	12.6 (112)	31.9 (283)	44.8 (397)	8.2 (73)	1.5 (13)	1.0 (9)	2.60 (1.08)

Note: MLTA=Much Lower Than Average; LTA= Lower Than Average; A=Average; HTA= Higher Than Average; MHTA=Much Higher Than Average. Values represent % (n).

[a]This item asked based on participant's reported sex.

Table A.11

Complete Demographics of the Participant Sample Used for Dissertation Analyses

Gender	Group	Male	Female
	19-39 years old	43.1 (151)	56.9 (199)
	40-59 years old	35.9 (113)	64.1 (202)
	60+ years old	42.9 (98)	56.1 (125)
	Overall	40.8 (362)	59.2 (526)

Adopted	Group	Yes	No
	19-39 years old	6.0 (21)	94 (329)
	40-59 years old	7.9 (25)	92.1 (290)
	60+ years old	2.2 (5)	97.8 (218)
	Overall	5.7 (51)	94.3 (837)

Relationship Status	Group	Single	Married	Widowed	Divorced/Sep	Partnered/LTR
	19-39 years old	36.3 (127)	34.6 (121)	0.0 (0)	5.1 (18)	24.0 (84)
	40-59 years old	14.6 (46)	61.0 (192)	1.6 (5)	12.4 (39)	10.5 (33)
	60+ years old	5.4 (12)	66.8 (149)	6.3 (14)	12.6 (28)	9.0 (20)
	Overall	20.8 (185)	52.0 (462)	2.1 (19)	9.6 (85)	15.4 (137)

Biological Children	Group	Yes	No
	19-39 years old	18.9 (66)	81.1 (284)
	40-59 years old	60.6 (191)	39.4 (124)
	60+ years old	78.5 (175)	21.5 (48)
	Overall	48.6 (432)	51.4 (456)

Number of Biological Children	Group	1	2	3	4	5	6	7+
	19-39 years old	51.5 (34)	42.4 (28)	4.5 (3)	1.5 (1)	0.0 (0)	0.0 (0)	0.0 (0)
	40-59 years old	25.7 (49)	45.5 (87)	21.5 (41)	5.2 (10)	2.1 (4)	0.0 (0)	0.0 (0)
	60+ years old	17.7 (31)	48.6 (85)	25.7 (45)	2.3 (4)	4.0 (7)	1.1 (2)	0.6 (1)
	Overall	26.4 (114)	46.3 (200)	20.6 (89)	3.5 (15)	2.5 (11)	0.5 (2)	0.2 (1)

Table Continues

Table A.11 continued

Complete Demographics of the Participant Sample Used for Dissertation Analyses

Are any Biological Children under 18?	Group	Yes			No		
	19-39 years old	95.5 (63)			4.5 (3)		
	40-59 years old	44.0 (84)			56.0 (107)		
	60+ years old	0.6 (1)			99.4 (174)		
	Overall	34.3 (148)			65.7 (284)		
Hispanic/ Latino	Group	Yes			No		
	19-39 years old	6.9 (24)			93.1 (3.26)		
	40-59 years old	5.1 (16)			94.9 (299)		
	60+ years old	1.3 (3)			98.7 (220)		
	Overall	4.8 (43)			95.2 (845)		
Race	Group	Am Indian /Native Alaskan	Asian	Black or African American	Hawaiian or Pacific Islander	White	Other
	19-39 years old	3.1 (11)	9.7 (34)	3.7 (13)	1.4 (5)	86.6 (303)	7.4 (26)
	40-59 years old	1.9 (6)	2.2 (7)	3.8 (12)	0.3 (1)	92.4 (291)	4.8 (15)
	60+ years old	3.6 (8)	0.0 (0)	1.3 (3)	0.4 (1)	95.5 (213)	3.1 (7)
	Overall	2.8 (25)	4.6 (41)	3.2 (28)	0.8 (7)	90.9 (807)	5.4 (48)
Household Income Past 12 months	Group	<$40,000	$40,000-$69,999	$70,000-$99,999	$100,000-$199,000	$200,000-$500,000	>$500,000
	19-39 years old	24.6 (93)	16.3 (57)	18.0 (63)	29.1 (102)	8.3 (29)	1.7 (6)
	40-59 years old	11.8 (36)	16.0 (49)	20.6 (63)	36.3 (111)	12.4 (38)	2.9 (9)
	60+ years old	12.7 (28)	23.1 (51)	22.6 (50)	28.1 (62)	12.2 (27)	1.4 (3)
	Overall	17.9 (157)	17.9 (157)	20.1 (176)	31.4 (275)	10.7 (94)	2.1 (18)

Table Continues

Table A.11 continued

Complete Demographics of the Participant Sample Used for Dissertation Analyses

Highest Level of Ed.	Group	Grade Sch.	HS/ GED	Some College	College Degree	Some Grad Sch.	Master's Degree	Some Doc. Work	PhD, DSc, EdD	Doc. Equiv.
	19-39 years old	0.3 (1)	2.9 (10)	14.0 (49)	37.1 (130)	12.0 (42)	18.0 (63)	5.1 (18)	6.0 (21)	4.5 (16)
	40-59 years old	0.0 (0)	2.9 (9)	17.8 (56)	31.1 (98)	11.7 (37)	20.3 (64)	2.2 (7)	6.7 (21)	7.3 (23)
	60+ years old	0.9 (2)	4.0 (9)	20.2 (45)	17.9 (40)	11.7 (26)	24.7 (55)	3.6 (8)	8.5 (19)	8.5 (19)
	Overall	0.3 (3)	3.2 (28)	16.9 (150)	30.2 (268)	11.8 (105)	20.5 (182)	3.7 (33)	6.9 (61)	6.6 (58)

Current Employment Status	Group	Full Time	Part-time	Retired	Self-employed	Unemployed	Student	Not working by choice
	19-39 years old	62.9 (220)	12.6 (44)	0.6 (2)	5.7 (20)	8.0 (28)	20.3 (71)	4.6 (16)
	40-59 years old	58.7 (185)	6.7 (21)	11.1 (35)	13.0 (41)	7.3 (23)	1.6 (5)	9.2 (29)
	60+ years old	22.4 (50)	9.0 (20)	63.2 (141)	7.6 (17)	2.7 (6)	0.0 (0)	3.6 (8)
	Overall	51.2 (455)	9.6 (85)	20.0 (178)	8.8 (78)	6.4 (57)	8.6 (76)	6.0 (53)

Note: Values represent % (n).

APPENDIX B
DATA DISTRIBUTION AGREEMENT WITH IMPACT OF PERSONAL GENOMICS STUDY GROUP

The Impact of Personal Genomics (PGen) Study

Data Distribution Agreement

The undersigned parties hereby enter into this Data Distribution Agreement (DDA) as of the date specified on the final page hereof. For correspondences related to this agreement please contact:

Erica Schonman
eschonman@genetics.med.harvard.edu
617-264-5885

INTRODUCTION

The NIH-funded Impact of Personal Genomics (PGen) Study is a longitudinal survey of consumers of two personal genetic testing companies, 23andMe and Pathway Genomics, to gather empirical data about the characteristics of these consumers and the psychological, behavioral, and health impact associated with personal genetics services. Data may also include participants' personal genetic risk information, provided with participants' consent.

The undersigned parties entering into this DDA include the following:

- Recipient(s): the researcher(s) and institution or other entity receiving access to the PGen Study Data.
    - If the individual requesting data access is a student or trainee, he or she must identify a faculty mentor to be the responsible party. The student/trainee and faculty mentor must co-sign this document as Recipients.
- Joint Principal Investigator Dr. Robert C. Green at Brigham and Women's Hospital and Harvard Medical School, and Joint Principal Investigator Dr. J. Scott Roberts at the University of Michigan School of Public Health
- Co-Investigators from 23andMe and Pathway Genomics

To protect the confidentiality and privacy of PGen participants, Recipients granted access to study data must adhere to the requirements of this DDA. Failure to comply with this DDA could result in its termination and denial of further access to PGen Study Data, and may leave violators liable to legal action, for instance on the part of PGen participants, corporate research partners, or the U.S. Government.

TERMS AND CONDITIONS

1. Data. Data including but not limited to any and all information derived from survey materials, genetic risk information and any and all data derived from statistical analyses linking genetic data with other study data will be kept confidential and will not be shared with anyone other than the Recipient(s) authorized in writing. **"Data"** refers to any and all study data, either obtained directly from PGen participants or obtained from third parties as authorized by the participants, with oversight by the Partners Human Research Committee.

2. Research Project. This data will be used by the Recipient(s) only in the below Research Project (list name of Research Project and objective of research project below):

Describing Age Group Differences in Decision Making Related to Genetic Information.

Objective: Characterize and describe relationships and differences in genetic knowledge, interests, perceptions, attitudes, and decision making among three age groups of PGen study participants.

2.1 If any aspect of the Research project e.g. data analysis is to be performed by any entity other than the Recipient(s) such entity is to be named below:

_____

3. Non-transferability. The Data specified in this agreement should not be distributed and transferred to any other individuals or entities unspecified in this agreement regardless of its intended use. A separate agreement would need to be obtained and approved by both Principal Investigators and by at least one representative from each of the genetic testing companies, 23andMe and Pathway Genomics.

4. Collaboration. The Recipient agrees not to publish: any comparative data of 23andMe and Pathway Genomics resulting from the PGen Study, any company-specific data, or any data from which company-specific data could be inferred, without prior written permission from the Principal Investigators and Co-Investigators from both 23andMe and Pathway Genomics. The Recipient agrees not to make any public statements that compare the companies based on data that is derived from the PGen Study dataset.

5. Review of Analyses. At the discretion of the Principal Investigators, analyses of PGen Data performed by the Recipient(s) may be subject to review by the PGen Study team prior to submission for publication.

6. Manuscript Review. The Recipient agrees that any scientific publication of PGen Data will be reviewed and approved in writing by the Principal Investigators, and shared with Co-Investigators from 23andMe and Pathway Genomics for comment prior to submission for publication.

7. Acknowledgements. The Recipient must acknowledge the Data gathered by the PGen Study staff in any and all oral and written presentations, disclosures, and publications resulting from any and all analyses of Data, by including "**for the PGen Study Group**" and the PGen Study grant number **HG005092** at the end of the author list or in an Acknowledgements section.

8. Anonymity. The Recipient agrees that Data will not be used, either alone or in conjunction with any other information, in any effort to determine the individual identities of any of the participants from whom Data were obtained or derived.

9. Security. The Recipient should be aware of computer and data security, and must make sure that the information is protected with industry standard data protection practices.

REQUIRED SIGNATURES

Rosanne H. Pruitt, PhD, APRN, FNP-BC, Professor — 01/14/2016

Recipient Name & Title (Faculty only) — Date

Recipient Signature

1/14/2016

Student Co-signature (if applicable) — Date

Collaborator Co-signature (if applicable) — Date

Collaborator Co-signature (if applicable) — Date

Robert C. Green, MD, MPH
Joint Principal Investigator — Date

J. Scott Roberts, PhD
Joint Principal Investigator — Date

23andMe Co-Investigator Name & Title — Date

23andMe Co-Investigator Signature

Pathway Genomics Co-Investigator Name & Title — Date

Pathway Genomics Co-Investigator Signature

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