

Three Essays on Health and Health Care in Society: Public Values, Genomic Policies,
and Socio-technical Futures of Our Lifespan

by

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A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved March 2019 by the
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ARIZONA STATE UNIVERSITY

May 2019

ABSTRACT

Each of the three essays in this dissertation examine an aspect of health or health care in society. Areas explored within this dissertation include health care as a public value, proscriptive genomic policies, and socio-technical futures of the human lifespan.

The first essay explores different forms of health care systems and attempts to understand who believes access to health care is a public value. Using a survey of more than 2,000 U.S. citizens, this study presents statistically significant empirical evidence regarding values and other attributes that predict the probability of individuals within age-based cohorts identifying access to health care as a public value. In the second essay, a menu of policy recommendations for federal regulators is proposed in order to address the lack of uniformity in current state laws concerning genetic information. The policy recommendations consider genetic information as property, privacy protections for re-identifying de-identified genomic information, the establishment of guidelines for law enforcement agencies to access nonforensic databases in criminal investigations, and anti-piracy protections for individuals and their genetic information. The third and final essay explores the socio-technical artifacts of the current health care system for documenting both life and death to understand the potential for altering the future of insurance, the health care delivery system, and individual health outcomes. Through the development of a complex scenario, this essay explores the long-term socio-technical futures of implementing a technology that continuously collects and stores genetic, environmental, and social information from life to death of individual participants.

ACKNOWLEDGMENTS

I would like to thank my committee for their tremendous help and guidance throughout the past several years. I would like to thank Barry Bozeman for serving as my committee chair and for allowing me to use the 2016 Citizen Values Project dataset for Essay 1.

Additionally, I would like to thank Barry Bozeman, Monica Gaughan, Mary Feeney, and other colleagues from the 6th Biennial Public Values Consortium as well as the 2018 Public Management Research Conference for providing helpful feedback on Essay 1.

From Essay 2's inception to the final product, I can't thank Bob Cooke-Deegan enough for providing his expertise and guidance in both genomic policy and writing. He graciously gave his time and energy in connecting me with various opportunities, agencies, and experts including the 2016 Partnering for Cures Conference as well as a tour around Washington D.C. to meet various agencies related to science and technology policy. Thank you to Bob Cooke-Deegan, Mary Majumder, Dan Sarewitz, and Jason Robert for reviewing Essay 2 in detail and providing extremely helpful feedback.

Additionally, thank you to Jessica Roberts for taking time during her sabbatical to discuss property rights and progressive genomic ownership. Finally for Essay 2, thank you to my professors (Bob Cooke-Deegan, Jenny Reardon, and Paul Griffiths) and colleagues from the 2017 Univie Summer School/Scientific World Conceptions for Genomics:

Philosophy, Ethics, and Policy for two extraordinary weeks of learning, debating, and sharing of culture and ideas. For Essay 3, thank you to Gary Marchant and Yvonne Stevens for their thorough review and comments on this paper. In addition, thank you to special issue editors for *Futures*, Knud Böhle and Kornelia Konrad, for their insights and advice regarding this essay. Thank you to Dan Sarewitz for his comments and

recommendations for strengthening Essay 3. Thank you to Vic Trastek for your encouragement, advice, and mentorship over the past several years. Finally, I would like to thank the faculty and staff of the School for the Future of Innovation in Society as well as the Center for Organization Research and Design (CORD) for supporting and funding several opportunities to learn and present at national or international conferences and workshops.

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CHAPTER 1

INTRODUCTION: HEALTH AND HEALTH CARE IN SOCIETY

Health and health care are vital components of any society. Life expectancy, infant mortality, universal health coverage, and spending per capita on health care are just some of the outcomes used to measure a society's health and well-being by the Organization for Economic Co-operation and Development (OECD). The amount a country spends on health care per individual does not equate to having the best overall health outcomes compared to other countries (OECD, 2017). Many social factors external to the amount spent on health care can influence the health and well-being of a society. These factors are known as the social determinants of health and include stress, early life, the social gradient, social exclusion, work, unemployment, social support, addiction, food, clean water, education, housing, and transportation (Schroeder, 2007; Marmot, 2005). Gross inequalities in health exists between countries with an extreme example being a thirty-four year difference in life expectancy between Japan and Sierra Leone (Marmot, 2005). Even within countries, there are gross inequalities in health between the most and least advantaged individuals (Marmoth, 2005). Within the United States, where a person lives (i.e. their zip code), their ethnicity and race, and their class have the potential of influencing their life expectancy up to twenty years (Robert Wood Johnson Foundation, 2019; Marmoth, 2005; McGinnis et. al., 2002).

Spending for medical treatments within the U.S. has dominated health policy and the overall landscape for health and health care, but arguments have been made to shift the focus from a health care agenda to a health agenda that targets health promotion and the prevention of disease (McGinnis et. al., 2002). At a population level, domains

contributing to early deaths within the U.S. are estimated to be 40% for behavioral patterns, 30% for genetic predispositions, 15% for social circumstances, 10% for shortfalls in medical care, and 5% for environmental exposures (McGinnis et. al., 2002).

Figure 1 illustrates the percent estimates of the various domains that influence health adapted from McGinnis et. al., (2002).

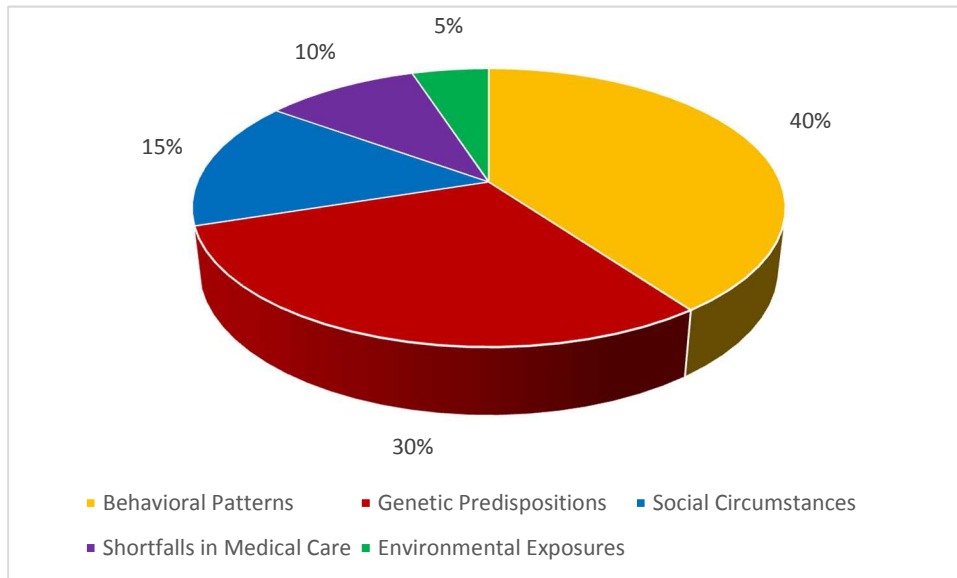


Figure 1: Impacts of Various Domains on Early Deaths in the U.S.

In 2006, the U.S. spent an estimated \$2.1 trillion or 16% of its Gross Domestic Product (GDP) on health care and a little over a decade later in 2017, health expenditures for the U.S. were estimated at \$3.5 trillion or nearly 18% of GDP (Centers for Medicare and Medicaid Services, 2018; Poisal et. al., 2007). In eleven years, the U.S. has managed to increase its health care expenditures by \$1.4 trillion or 2% GDP. Although this dissertation primarily focuses on genetics, precision medicine, and health care, it is important to note that the health of a society is strongly influenced by other factors like behavior, social circumstances, and the environment.

The first essay uses a lens of public administration to examine health care as a public value. Achieving high value for each patient is a core tenet within the field of health care, yet health care remains a divisive issue within the United States due to numerous aspects including access and affordability. The importance of value within health care often focuses on the individual patient with less emphasis on health care as a public value. For this paper, public values are “those values providing normative consensus about (a) the rights, benefits, and prerogatives to society, the state and one another...; and (c) the principles on which governments and policies should be based” (Bozeman, 2007, p 13). This research explores different forms of health care systems and attempts to understand who believes access to health care is a public value. Using a survey of more than 2,000 U.S. citizens, this study presents statistically significant empirical evidence regarding values and other attributes that predict the probability of individuals within age-based cohorts identifying access to health care as a public value. This study also defines and isolates public value deniers and explores their public values beliefs including access to adequate health care. An analysis is also performed between the values that individuals are willing to self-sacrifice compared to those they believe ought to be provided by a society for its citizens. The investigation reveals a stark contrast between individual values and public values related to access to adequate health care. A theory of public values dissonance is developed due to the incongruent beliefs that individuals possess regarding health care for themselves compared to the right of health care for all.

Using lenses including bioethics and science and technology policy, the second essay proposes a menu of policy recommendations for federal regulators to address the

lack of uniformity in current state laws concerning genetic information. The policy recommendations consider genetic information as property, privacy protections for re-identifying de-identified genomic information, the establishment of guidelines for law enforcement agencies to access nonforensic database in criminal investigations, and anti-piracy protections for individuals and their genetic information.

In 2012, the U.S. Presidential Commission for the Study of Bioethical Issues recommended a consistent baseline of state and federal government privacy protections for whole genome sequence information. Federal law does not grant individuals exclusive property rights to their genetic information, but five states currently recognize genetic information as the property of the individual from whom it came: Alaska, Colorado, Florida, Georgia, and Louisiana.

This paper seeks to bolster the protections for individuals and their genetic information while reducing uncertainty, variability, and inconsistency from state to state. These recommendations are based on historical, ethical, legal, political, and social events that involve current laws governing the uses of human body parts, samples, and data, including blood, tissues, organs, genes, and genetic information.

The first policy recommendation calls for property rights to be granted to individuals regarding their genetic information. The second recommendation calls for the establishment of statutory law to proscribe the unauthorized acquisition, collection, storage, access, analysis, disclosure, surreptitious use, or reproduction of an individual's genetic information. A third and final recommendation is a privacy rule that (a) prohibits the unauthorized re-identification of an individual using their de-identified genetic information unless re-identification could lessen or prevent a serious and imminent threat

to the health and safety of the individual or others and (b) prohibits the use of nonforensic databases for the identification of suspects as part of a criminal investigation unless a threshold is met within established national guidelines for relevant and reasonable cause. Violators who infringe these proposed policies should be subject to criminal penalties as well as tort liability through civil processes.

The third and final essay uses lenses of Science and Technology Studies (STS), future studies, and scenario planning to explore the future of the human lifespan. The enactment of the 21st Centuries Cures Act as a law and the implementation of the Precision Medicine Initiative's million person cohort within the United States illustrates the relevance of precision medicine to the construction of future socio-technical systems within health care and all of our lives. The socio-technical futures of precision medicine has the potential to radicalize the process and governance for collecting, storing, and networking information to document and alter the human lifespan. This study explores the socio-technical artifacts of the current health care system for documenting both life and death to understand the potential for altering the future of insurance, the health care delivery system, and individual health outcomes. Through the development of a complex scenario, this study will explore the long-term socio-technical futures of implementing a technology that continuously collects and stores genetic, environmental, and social information from life to death of individual participants.

CHAPTER 2

ESSAY 1: IS HEALTH CARE A PUBLIC VALUE?

To understand the various forms of health coverage around the world, an exploration of the different types of health care delivery systems is necessary. There are four basic models of health care delivery systems around the world despite the existence of nearly 200 countries. In his book, T.R. Reid (2010) documents the four basic models of health care systems which are the Beveridge model, the Bismarck model, the National Health Insurance model, and the Out-of-Pocket model. The Beveridge model is named after William Beveridge, the designer of Britain's National Health Service - a service where the government is the sole payer of health care (Reid, 2010). Variations of the Beveridge model can be found in Spain, New Zealand, Hong Kong, Great Britain, and Cuba (Reid, 2010). The Bismarck model, named after the Prussian Chancellor Otto von Bismarck, is an insurance system that is highly regulated by the government, jointly funded by employees and employers, mandated to cover everyone, and doesn't make a profit (Reid, 2010). Germany, Switzerland, Japan, the Netherlands, France, and Belgium all have variations of the Bismarck model (Reid, 2010). The National Health Insurance model exists in Canada, Taiwan, and South Korea, and it is a universal insurance program funded by every citizen and run by the government (Reid, 2010). The Out-of-Pocket model is typically found in underdeveloped and non-industrialized countries where patients are expected to pay out-of-pocket due to no insurance or governmental plan (Reid, 2010). The U.S. health care system is considered a mixed system due to it being a patchwork of all four systems.

The Organization for Economic Co-operation and Development (OECD) provides information regarding health care and health outcomes for 35 member countries as well as several other partnering countries. Universal or near-universal health coverage has been realized by 82.8% of all OECD countries with the exception of six: Chile, Greece, Mexico, Poland, the Slovak Republic, and the United States (OECD, 2017). Health coverage is considered universal if the entire population of the country is covered by 95% of core health care services (OECD, 2017). The U.S. is one of the three lowest providers of population wide coverage of all OECD countries and currently spends more on health per capita and GDP than any other OECD country (OECD, 2017). The United States spent 17.2% of its GDP on health and USD \$9,892 for each of its residents in 2016 (OECD, 2017). According to the OECD (2017), the level of health spending in the U.S. was almost 25% higher than the next biggest spender and two-and-a-half times the average level of spending for all OECD countries. Despite the significant spending on health, the United States has an infant mortality rate of 5.8 deaths per 1,000 live births as compared to the current OECD average of 3.9 deaths per 1,000 live births placing it at 33 out of 44 countries (OECD, 2017). Additionally, life expectancy within the U.S. has seen modest gains as compared to other OECD countries with the U.S. being at 78.8 years of age, but it is still below the OECD average of 80.6 years of age (OECD, 2017). Life expectancy at birth in the U.S. ranks 28 out of 44 countries (OECD, 2017).

Tracking health outcomes and assessing universal health coverage of populations are two methods for comparing health quality between countries. Another measure that allows comparing various nations is the Gini coefficient. The Gini coefficient was developed by Corrado Gini and serves as a measure of inequality through the calculation

of a single number that describes the distribution of wealth or income for a country (Gini, 1912). The Gini coefficient can range from zero to 100 with a score of zero indicating perfect equality in income distribution and a score of 100 signifying perfect inequality for distribution of income (CIA, 2019). There are currently five OECD countries who have Gini coefficients greater than 40 including Chile (47.7), Mexico (43.4), Turkey (41.9), the United States (41.5), and Israel (41.4) (CIA, 2019). Note that three of the five countries with Gini coefficients greater than 40 (Chile, Mexico, and the United States) were also listed for not having universal health coverage.

Table 1 provides a summary of all OECD countries including achievement of universal health coverage (OECD, 2017), Gini coefficients (CIA, 2019), estimates of civilian firearms per 100 persons (Small Arms Survey, 2019), and rate of all gun deaths per 100,000 people (Alpers & Wilson, 2013). Health care and guns will be addressed in a later section of the paper.

Table 1

Universal Health Care, Gini Coefficients, Estimated Civilian Gun Ownership, and Rate of Gun Deaths of OECD Countries

Country	Universal Health Care	Gini Coefficient	Estimate of Civilian Firearms per 100 Persons	Rate of All Gun Deaths per 100,000 people
Australia	Yes	34.7	14.5	1.04
Austria	Yes	30.5	30.0	2.90
Belgium	Yes	27.7	12.7	1.24
Canada	Yes	34	34.7	2.13
Chile	No	47.7	12.1	2.98
Czech Republic	Yes	25.9	12.5	1.77
Denmark	Yes	28.2	9.9	1.47
Estonia	Yes	32.7	5.0	1.49
Finland	Yes	27.1	32.4	2.48
France	Yes	32.7	19.6	2.65
Germany	Yes	31.7	19.6	1.01
Greece	No	36.0	17.6	1.71
Hungary	Yes	30.4	10.5	0.81
Iceland	Yes	27.8	31.7	0.30
Ireland	Yes	31.8	7.2	0.96
Israel	Yes	41.4	6.7	1.24
Italy	Yes	35.4	14.4	1.27
Japan	Yes	32.1	0.3	0.02
Korea	Yes	31.6	0.2	0.06
Latvia	Yes	34.2	10.5	1.44
Luxembourg	Yes	33.8	18.9	1.43
Mexico	No	43.4	12.9	10.72
Netherlands	Yes	28.2	2.6	0.46
New Zealand	Yes	36.2	26.3	1.22
Norway	Yes	27.5	28.8	1.22
Poland	No	30.8	2.5	0.24
Portugal	Yes	35.5	21.3	1.43
Slovakia	No	26.5	6.5	1.89
Slovenia	Yes	25.4	15.6	1.97
Spain	Yes	36.2	7.5	0.60
Sweden	Yes	29.2	23.1	1.60
Switzerland	Yes	32.3	27.6	7.40
Turkey	Yes	41.9	16.5	2.36
United Kingdom	Yes	33.2	4.6	0.23
United States	No	41.5	120.5	11.96

PUBLIC VALUES

Due to the limitations of public interest theory, public values theory gained traction and favorability as documented by several scholarly works that trace the

immurgence and evolution of public values (Beck Jørgensen & Rutgers, 2015; Van der wal, Nabatchi, & De Graaf, 2015; Nabatchi, 2012; Bozeman, 2007). Public interest theory began to be dismissed in the 1950's due to its ambiguity, vagueness, and lack of measurability (Bozeman, 2007). As public values theory emerged as a potential replacement for public interest theory, a clear, unambiguous definition for public values was necessary.

Although the words public value and public values are nearly identical, their theories are dissimilar. The public value framework developed by Mark Moore emphasizes public sector management and the value an organization creates for society (Moore, 1995). In contrast, the public values framework created by Barry Bozeman emphasizes a normative political framework and defined a society's public values as "those providing normative consensus about (a) the rights, benefits, and prerogatives to which citizens should (and should not) be entitled; (b) the obligations of citizens to society, the state, and one another; and (c) the principles on which governments and policies should be based" (Bozeman, 2007, p. 13). Several articles comparing and contrasting the two frameworks serve to inform scholars of the differing theories associated with public value and public values in response to the potential confusion caused by the naming similarity (Bozeman & Johnson, 2015; Bryson, Crosby, & Bloomberg, 2014; Alford & O'Flynn, 2009).

Public values framework, public value mapping, and public values have been used to explore various scientific, health care, and medical topics including science outcomes (Bozeman, 2003), cancer (Gaughan, 2003), influenza vaccine shortage (Feeney & Bozeman, 2007), nanomedicine (Slade, 2011), science policy and evaluation

(Bozeman & Sarewitz, 2011; Bozeman & Sarewitz, 2005), and human organ transplantation systems (Wang, 2016). This study seeks to contribute to public values research by asking the question – is access to adequate health care a public value? This paper began with a global comparison of OECD countries who have achieved universal health coverage (Table 1) and narrows to a national analysis for one of the OECD countries who hasn't achieved universal health coverage – the United State.

VALUE IN HEALTH CARE

Value is defined in various ways depending on the field of study. This paper explores value and public values in the fields of health care and public administration. The notion of using public values within health care to set priorities is not a new concept (Mullen, 1999; Hadorn, 1991). Over time, the concept of value within health care has evolved to be defined as the amount spent (per dollar) to achieve health outcomes or more simply put outcomes relative to costs (Porter & Teisberg, 2006). After a long period of being misunderstood and unmeasured (Porter, 2010), value-driven outcomes (Lee et. al., 2016) as well as value-based health care delivery systems and reforms (Porter & Lee, 2016; Porter, 2009; Porter, 2008) are finally being realized through experience groups (Silverman, 2017), measuring outcomes that matter to patients (Teisberg & Wallace, 2015), and improving functional outcomes measures (Wallace & Teisberg, 2016). Despite this progress, many individuals still don't have access to the health services they need and risk impoverishment or financial ruin due to seeking health care (Dye, Reeder, & Terry, 2013). This is the antithesis of universal health coverage.

HYPOTHESES

Vaccines, gun violence, reproductive health, and health reform are all important public health issues and topics of focus for the American Public Health Association (APHA, 2019). However, the right to health care for all citizens is a contentious topic within the United States. Headlines abound, especially during national elections, debating health care as a right or a privilege for all citizens. There are several fiercely debated topics within the U.S. involving health care including the type of health care system that should exist, the exorbitant amount spent on health care, and poor health outcomes despite the vast amounts of money poured into the health care system. According to the Centers for Medicare and Medicaid Services (2018), the national health expenditure for the U.S. totaled \$3.5 trillion in 2017 which translates to \$10,739 for each person and nearly 18% of Gross Domestic Product (GDP).

Although this paper can't answer if access to adequate health care is a public value, it will provide insights into the beliefs of a sampling of U.S. citizens regarding access to adequate health care as a public value. Specifically, this paper will explore five age-based cohorts to determine who does and who doesn't think access to adequate health care is a public value. This paper will also compare and contrast citizens' beliefs about other potential public values including gun ownership, women's right to terminate an unwanted pregnancy, and racial and ethnic diversity and how they relate to access to adequate health care.

HEALTH CARE AND GUNS

Guns have been described as a health care issue due to the annual number of deaths they cause in accidents, suicides, and homicides ("Guns," 2014; Miller & Hemenway, 2008). The ability to possess or own a gun varies per country, and the rate of

deaths per year by guns depends on the availability and use of guns by each country's citizenry. As with health care spending, the U.S. leads the OECD countries in annual gun deaths and estimated ownership of civilian firearms. In 2017, U.S. civilians were estimated to have 120.5 firearms per 100 persons (Small Arms Survey, 2019). In 2016, the U.S. had approximately 11.96 gun deaths per 100,000 people (Alpers & Wilson, 2013). Within the U.S., health care and gun policies are two of the most important issues for registered voters. According to an October 2018 Gallup Midterm Election poll, health care was the most important issue for 80% of registered voters (Newport, 2018). Gun policy ranked fifth at 72% for the most important issues for midterm voters (Newport, 2018). Gun control advocates within the U.S. have asserted rational public health benefits over the past twenty years in an attempt to tighten gun regulations (Filindra & Kaplan, 2016).

Hypothesis 1: Individuals who believe that gun ownership is a public value have a decreased predicted probability of believing access to adequate health care is a public value.

Hypothesis 2: Individuals who believe access to adequate health care is a public value have a decreased predicted probability of believing gun ownership is a public value.

HEALTH CARE AND ABORTION

The services and components required for a country to achieve universal health coverage can change over time. The World Health Organization's executive board adopted a resolution in February 2019 that includes access to health care services for reproductive and sexual health (Oas, 2019). Reproductive health as an umbrella

terminology can include procedures like abortion. Inclusion of abortion as part of universal health coverage is a polarizing and political topic, but national and global advocates for abortion as a requirement for universal health coverage insist it is reproductive right (Oas, 2019; Grimaldi, 2017). Individuals who oppose including abortion as a part of universal health coverage may fear that providing access to the service may increase abortions, but one study reported a decrease in abortion rates for two consecutive years after Massachusetts enacted health care reform legislation which included reproductive health (Whelan, 2010).

Hypothesis 3: Individuals who believe that women's right to terminate an unwanted pregnancy is a public value have an increased predicted probability of believing access to adequate health care is a public value.

HEALTH CARE AND RACE

The intersection of health care policy preference and racial attitudes can provide insight into how opinions about health care can be influenced by racial resentment, prejudice, or racism. Strong opposition from Republicans and conservative Democrats to President Barack Obama's Affordable Care Act resulted in claims that racism was the actual reason for the opposition (Hanania, 2011). Several empirical studies sought to understand if opinions about health care had been racialized. One study revealed that racial prejudice predicted opposition to Obama's health care reform policies (Knowles, Lowery, & Schaumberg, 2010). Henderson and Hillygus (2011) found that racial attitudes had a large and significant effect on health care attitudes especially for individuals possessing the greatest racial resentment. Tesler (2012) demonstrated that racial attitudes played a significant role in influencing health care opinions. Specifically,

the study highlighted how the racial divide regarding health care opinion had increased by 20 percentage points over a sixteen-year period from 1993-94 to 2009-10 as well as the racialization of health care policies when attributed to former President Obama compared to the same policies being attributed to former President Clinton (Tesler, 2012). A final study concluded that that attitudes towards universal health care and other social welfare policies perceived as providing benefits to racial minorities can be predicted by subtle racial prejudice (Shen & LaBouff, 2016).

Hypothesis 4: Individuals who believe that racial and ethnic diversity is a public value have an increased predicted probability of believing access to adequate health care is a public value.

HEALTH CARE INITIATIVES

The Lancet's Commission on Essential Medicines Policies summarized the importance and interconnectedness of essential medicines including vaccines, health care systems, health care, and society in the closing of the executive summary which stated, "Without essential medicines, health systems cannot truly help people who fall ill, live with chronic disease, and go through various stages of life and death. Without strong health systems, populations cannot realise their right to health" (Wirtz et. al., 2017, p. 406).

The 2015 UN Sustainable Development Goals (SDG) (2019) list seventeen goals including Sustainable Development Goal 3 (SDG 3) which is focused on good health and well-being. By 2030, the targets for SDG 3 are slated to be achieved including universal health coverage and access to essential medications and vaccinations for all (UN SDG, 2019). Even if vaccinations are made available to all, a growing number of individuals

are refusing to vaccinate their children. The decision to vaccinate or refuse vaccinations is explored by one study that finds a direct effect between attitudes towards vaccinations and an individual's ideology (Baumgaertner et. al., 2018). If individuals are supportive of health care initiatives, then those individuals may be more likely to support health care as a public value. Individuals who don't support health care initiatives that are linked to public health issues like vaccinations may be more likely to support gun ownership due to alignment with personal ideology.

Hypothesis 5: Individuals who support enacted public values related to health care initiatives (i.e. vaccines and not denying health benefits at a faith based organization) have an increased predicted probability of supporting health care as a public value.

Hypothesis 6: Individuals who deny enacted public values related to health care initiatives (i.e. no vaccines and denial of health benefits at a faith based organization) have an increased predicted probability of supporting gun ownership as a public value.

PUBLIC VALUES SACRIFICE

The public values classification scheme developed by Bozeman (2017) asserts that a consensual public value exists when 90% or more of respondents support a candidate public value as a public value. A public value is considered contested when more than 50% but less than 90% of respondents support the candidate public value as a public value (Bozeman, 2017). If respondents were asked to sacrifice only one of their public values from a list of contested and consensual public values, a potential outcome could be that a consensual public value would be the least sacrificed due to reaching 90%

consensus or higher among respondents. Using the same logic, the most sacrificed public value among respondents would likely be a contested public value due to not obtaining a 90% consensus.

Hypothesis 7: The value that citizens are most willing to self-sacrifice will be a contested public value, and the value that citizens are least willing to self-sacrifice will be a consensual public value.

METHODS AND DATA

The 2016 Citizen Values Project surveyed 2,509 U.S. citizens using Amazon's Mechanical Turk (MTurk) crowdsourcing tool. The use of MTurk for social science and health care research is extensive and includes clinical populations (Shapiro et. al., 2013), genetic testing (Lillie et. al., 2015), behavioral research (Mason & Suri, 2012), and public administration and management scholarship (Stritch et. al., 2017). In addition, MTurk's reliability (Goodman et. al., 2013), demographic and political attributes of respondents (Huff & Tingley, 2015), ability to produce high-quality data (Buhrmester et. al., 2011), comparison with social media and in-person testing (Casler, et. al., 2013), use in experimental research (Paolacci et. al., 2010; Berinsky et. al., 2012), and the detection of nonhuman responses (Dupuis et. al., 2018) have all been topics of scholarly exploration.

The survey was framed using historical documents and speeches in order to ask participants their beliefs about specific public values. The use of historical documents to extract potential public values has been an endorsed method in public values research (Beck Jørgensen & Bozeman, 2007; Bozeman, 2002). For the survey, a public value was defined as "the rights and benefits to which all citizens should be entitled and which a society should work to provide." Fourteen anchored candidate public value statements

were presented to participants regarding liberty, freedom of speech, civil rights, public participation, freedom of religion, safety and security, gender equity, protection of minority interests, economic opportunity, privacy, racial and ethnic diversity, gun ownership, access to adequate health care, and women's rights to terminate a pregnancy. Participants were then asked to determine if they believed the candidate public value to be a public value. For this study the dependent variable was the candidate public value regarding access to adequate health care. To frame access to adequate health care as a candidate public value, Franklin Delano Roosevelt's 1944 State of the Union address was provided to participants:

“We have accepted, so to speak, a second Bill of Rights under which a new basis of security and prosperity can be established for all regardless of station, race, or creed. Among these: the right to adequate medical care and the opportunity to achieve and enjoy good health.”

Participants were then asked if access to adequate health care was a public value. Their response choice was coded 0 = No or 1 = Yes.

Using Bozeman's (2017) public values classification scheme, consensual public values (when 90% or more of the respondents indicated the candidate value as a public value) and contested public values (when more than 50% but less than 90% of respondents indicated the candidate value as a public value) were identified (Table 2). Access to adequate health care as a public value was supported by 2,132 respondents (84.97%) making it a contested public value.

Table 2

Consensual and Contested Public Values

Value	Considered A Public Value	
	Yes	No
<i>Consensual Public Value</i>		
Freedom of Speech	2,447 (97.53%)	62 (2.47%)
Liberty	2,438 (97.17%)	71 (2.83%)
Civil Rights	2,408 (95.97%)	101 (4.03%)
Political Participation	2,354 (93.82%)	155 (6.18%)
Freedom of Religion	2,330 (92.87%)	179 (7.13%)
Gender Equality	2,292 (91.35%)	217 (8.65%)
Safety and Security	2,270 (90.47%)	239 (9.53%)
<i>Contested Public Value</i>		
Protection of Minority Interests	2,161 (86.13%)	348 (13.87%)
Access to Adequate Health Care	2,132 (84.97%)	377 (15.03%)
Economic Opportunity	2,132 (84.97%)	377 (15.03%)
Privacy	2,057 (81.98%)	452 (18.02%)
Racial and Ethnic Diversity	1,795 (71.54%)	714 (28.46%)
Gun Ownership	1,601 (63.81%)	908 (36.19%)
Women's Prerogative to Terminate an Unwanted Pregnancy	1,564 (62.34%)	945 (37.66%)

Participants were also asked to self-sacrifice one of the fourteen public values. Specifically, the statement said, "Let us assume that you were somehow forced to sacrifice just 1 of the 14 values that we've provided in order to obtain the others. Which

one would you sacrifice?” Table 3 provides the results for the public values sacrifice exercise.

Table 3

Individual Sacrificed Values in Order of Least Sacrificed to Most Sacrificed

Value	Frequency	Percentage
Access to Adequate Health Care	7	0.28%
Liberty	11	0.44%
Civil Rights	16	0.64%
Economic Opportunity	39	1.55%
Safety and Security	49	1.95%
Racial and Ethnic Diversity	60	2.39%
Privacy	78	3.11%
Gender Equality	78	3.11%
Gun Ownership	79	3.15%
Political Participation	82	3.27%
Freedom of Speech	146	5.82%
Protection of Minority Interests	209	8.33%
Women’s Prerogative to Terminate an Unwanted Pregnancy	607	24.19%
Freedom of Religion	1,048	41.77%
Total	2,509	100.0%

Demographic information was also collected including age, income, gender, marital status, parental status, educational level, employment status, race, Hispanic/Latino/Spanish origin, political affiliation, parents’ education attainment, and U.S. born. Table 4 provides the demographic information and percentages for individuals who either supported or denied access to adequate health care as a public value where n=2509.

Table 4

*Demographics for Support and Denial of Access to Adequate Health Care as a Public**Value*

	Access to Adequate Health Care as a Public Value (n=2509)	
	Support	Deny
<u>Age</u>		
18-24	264 (10.5%)	43 (1.7%)
25-34	1013 (40.4%)	175 (7.0%)
35-44	472 (18.8%)	75 (3.0%)
45-54	226 (9.0%)	49 (2.0%)
55-64	125 (5.0%)	24 (1.0%)
65-74	31 (1.2%)	10 (0.4%)
75 or older	1 (0.0%)	1 (0.0%)
<u>Income</u>		
Less than \$10,000	288 (11.5%)	38 (1.5%)
\$10,000--\$19,999	247 (9.8%)	40 (1.6%)
\$20,000--\$29,999	299 (11.9%)	56 (2.2%)
\$30,000--\$39,999	314 (12.5%)	40 (1.6%)
\$40,000--\$49,999	252 (10.0%)	44 (1.8%)
\$50,000--\$59,999	208 (8.3%)	39 (1.6%)
\$60,000--\$69,999	153 (6.1%)	27 (1.1%)
\$70,000--\$79,999	121 (4.8%)	26 (1.0%)
\$80,000--\$89,999	70 (2.8%)	16 (0.6%)
\$90,000--\$99,999	51 (2.0%)	12 (0.5%)
\$100,000--\$149,999	104 (4.1%)	30 (1.2%)
More than \$150,000	25 (1.0%)	9 (0.4%)
<u>Gender</u>		
Male	1026 (40.9%)	223 (8.9%)
Female	1095 (43.6%)	150 (6.0%)
Other	2 (0.1%)	0 (0.0%)
Prefer not to disclose	9 (0.4%)	4 (0.2%)
<u>Marital Status</u>		
Married	871 (34.7%)	166 (6.6%)
Widowed	19 (0.8%)	3 (0.1%)
Divorced	157 (6.3%)	23 (0.9%)
Separated	32 (1.3%)	5 (0.2%)
Never married	379 (15.1%)	52 (2.1%)
Single	674 (26.9%)	128 (5.1%)
<u>Parental Status</u>		
No	1237 (49.3%)	211 (8.4%)
Yes	895 (35.7%)	166 (6.6%)
<u>Employment Status</u>		
Employed full time	1196 (47.7%)	248 (9.9%)
Employed part time	350 (13.9%)	57 (2.3%)
Unemployed looking for work	165 (6.6%)	22 (0.9%)
Unemployed not looking for work	159 (6.3%)	13 (0.5%)
Retired	44 (1.8%)	8 (0.3%)
Student	105 (4.2%)	14 (0.6%)

	Access to Adequate Health Care as a Public Value (n=2509)	
	Support	Deny
Disabled	55 (2.2%)	3 (0.1%)
Working multiple jobs	58 (2.3%)	12 (0.5%)
<i><u>Education Attainment</u></i>		
Less than high school	11 (0.4%)	3 (0.1%)
High school graduate	207 (8.3%)	33 (1.3%)
Some college	570 (22.7%)	87 (3.5%)
2-year degree	232 (9.2%)	40 (1.6%)
4-year degree	861 (34.3%)	152 (6.1%)
Professional degree	213 (8.5%)	56 (2.2%)
Doctorate	38 (1.5%)	6 (0.2%)
<i><u>Political Affiliation</u></i>		
Independent	486 (19.4%)	97 (3.9%)
Apolitical	105 (4.2%)	18 (0.7%)
Republic (“Weak” or “Strong”)	436 (17.4%)	164 (6.5%)
“Weak” Republican	262 (10.4%)	87 (3.5%)
“Strong” Republican	174 (6.9%)	77 (3.1%)
Democrat (“Weak” or “Strong”)	1016 (40.5%)	70 (2.8%)
“Weak” Democrat	500 (19.9%)	47 (1.9%)
“Strong” Democrat	516 (20.6%)	23 (0.9%)
Other Party Affiliation	89 (3.5%)	28 (1.1%)
<i><u>Parents’ Education Attainment</u></i>		
Neither finished high school	93 (3.7%)	6 (0.2%)
At least one finished high school	537 (21.4%)	83 (3.3%)
At least one attended college	422 (16.8%)	80 (3.2%)
At least one graduated from college	638 (25.4%)	134 (5.3%)
At least one obtained an advanced degree	417 (16.6%)	71 (2.8%)
Refuse/Don’t know	25 (1.0%)	3 (0.1%)
<i><u>Latino, Hispanic, or Spanish Origin</u></i>		
No	1986 (79.2%)	348 (13.9%)
Yes	146 (5.8%)	29 (1.2%)
<i><u>Race</u></i>		
White	1710 (68.2%)	308 (12.3%)
Black or African American	172 (6.9%)	26 (1.0%)
American Indian or Alaska Native	25 (1.0%)	4 (0.2%)
Asian	168 (6.7%)	27 (1.1%)
Native Hawaiian or Pacific Islander	3 (0.1%)	0 (0.0%)
Other	54 (2.2%)	12 (0.5%)
<i><u>US Born</u></i>		
No	102 (4.1%)	17 (0.7%)
Yes	2030 (80.9%)	360 (14.3%)

Table 5 compares supporters for access to adequate health care as a public value amongst themselves (n=2132). Table 5 also compares individuals who deny access to adequate health care as a public value with other deniers (n=377).

Table 5

Comparison of Percent Distribution between Support and Denial of Access to Adequate Health Care as a Public Value

	Access to Adequate Health Care as a Public Value (n=2509)	
	Support (n = 2132)	Deny (n = 377)
<u>Age</u>		
18-24	264 (12.4%)	43 (11.4%)
25-34	1013 (47.5%)	175 (46.4%)
35-44	472 (22.1%)	75 (19.9%)
45-54	226 (10.6%)	49 (13.0%)
55-64	125 (5.9%)	24 (6.4%)
65-74	31 (1.5%)	10 (2.7%)
75 or older	1 (0.0%)	1 (0.3%)
<u>Income</u>		
Less than \$10,000	288 (13.5%)	38 (10.1%)
\$10,000--\$19,999	247 (11.6%)	40 (10.6%)
\$20,000--\$29,999	299 (14.0%)	56 (14.9%)
\$30,000--\$39,999	314 (14.7%)	40 (10.6%)
\$40,000--\$49,999	252 (11.8%)	44 (11.7%)
\$50,000--\$59,999	208 (9.8%)	39 (10.3%)
\$60,000--\$69,999	153 (7.2%)	27 (7.2%)
\$70,000--\$79,999	121 (5.7%)	26 (6.9%)
\$80,000--\$89,999	70 (3.3%)	16 (4.2%)
\$90,000--\$99,999	51 (2.4%)	12 (3.2%)
\$100,000--\$149,999	104 (4.9%)	30 (8.0%)
More than \$150,000	25 (1.2%)	9 (2.4%)
<u>Gender</u>		
Male***	1026 (48.1%)	223 (59.2%)
Female***	1095 (51.4%)	150 (39.8%)
Other	2 (0.1%)	0 (0.0%)
Prefer not to disclose	9 (0.4%)	4 (1.1%)
<u>Marital Status</u>		
Married	871 (40.9%)	166 (44.0%)
Widowed	19 (0.9%)	3 (0.8%)
Divorced	157 (7.4%)	23 (6.1%)
Separated	32 (1.5%)	5 (1.3%)
Never married	379 (17.8%)	52 (13.8%)
Single	674 (31.6%)	128 (34.0%)
<u>Parental Status</u>		
No	1237 (58.0%)	211 (56.0%)
Yes	895 (42.0%)	166 (44.0%)
<u>Employment Status</u>		
Employed full time***	1196 (56.1%)	248 (65.8%)
Employed part time	350 (16.4%)	57 (15.1%)
Unemployed looking for work	165 (7.7%)	22 (5.8%)

	Access to Adequate Health Care as a Public Value (n=2509)	
	Support	Deny
Unemployed not looking for work	159 (7.5%)	13 (3.4%)
Retired	44 (2.1%)	8 (2.1%)
Student	105 (4.9%)	14 (3.7%)
Disabled	55 (2.6%)	3 (0.8%)
Working multiple jobs	58 (2.7%)	12 (3.2%)
*** > 5% difference		

Table 6 evaluates supporters and deniers of access to adequate health care as a public value and their support or denial of other candidate public values. The results compare and contrast consensual and contested public values among supporters and deniers of access to adequate health care as a public value. In contrast to table 2, the consensual and contested public values have been reclassified based on Bozeman's (2017) public values classification scheme.

Table 6

Access to Adequate Health Care as a Public Value Compared with Consensual and Contested Public Values

	Support Access to Adequate Health Care as a Public Value (n = 2132)	
	Support	Deny
<i>Consensual Public Values</i>		
Freedom of Speech	2089 (98.0%)	43 (2.0%)
Liberty	2086 (97.8%)	46 (2.2%)
Civil Rights	2072 (97.2%)	60 (2.8%)
Political Participation	2024 (94.9%)	108 (5.1%)
Gender Equality	2011 (94.3%)	121 (5.7%)
Freedom of Religion	1981 (92.9%)	151 (7.1%)
Safety and Security	1948 (91.4%)	184 (8.6%)
<i>Contested Public Values</i>		
Protection of Minority Interests	1897 (89.0%)	235 (11.0%)
Economic Opportunity	1883 (88.3%)	249 (11.7%)
Privacy	1796 (84.2%)	336 (15.8%)
Racial and Ethnic Diversity	1634 (76.6%)	498 (23.4%)
Women's Right to Terminate an Unwanted Pregnancy	1417 (66.5%)	715 (33.5%)
Gun Ownership	1310 (61.4%)	822 (38.6%)
<i>Deny Access to Adequate Health Care as a Public Value (n = 377)</i>		
	Support	Deny
<i>Consensual Public Values</i>		
Freedom of Speech	358 (95.0%)	19 (5.0%)
Liberty	352 (93.4%)	25 (6.6%)
Freedom of Religion	349 (92.6%)	28 (7.4%)
<i>Contested Public Values</i>		
Civil Rights	336 (89.1%)	41 (10.9%)
Political Participation	330 (87.5%)	47 (12.5%)
Safety and Security	322 (85.4%)	55 (14.6%)
Gun Ownership	291 (77.2%)	86 (22.8%)
Gender Equality	281 (74.5%)	96 (25.5%)
Protection of Minority Interests	264 (70.0%)	113 (30.0%)
Privacy	261 (69.2%)	116 (30.8%)
Economic Opportunity	249 (66.0%)	128 (34.0%)
<i>Not A Public Values</i>		
Racial and Ethnic Diversity	161 (42.7%)	216 (57.3%)
Women's Right to Terminate an Unwanted Pregnancy	147 (39.0%)	230 (61.0%)

Table 7 calculates the difference in percentage between contested and consensual public values based on support or denial of access to adequate health care as a public value. Consensual and contested public values are classified using the results presented in Table 2.

Table 7

Access to Adequate Health Care as a Public Value with Percent Differences between Consensual and Contested Public Values

	% Difference for Consensual and Contested Public Values Between Supporters and Deniers of Access to Adequate Health Care as a Public Value
<i><u>Consensual Public Values</u></i>	
Freedom of Speech	3.0%
Liberty	4.4%
Civil Rights	8.1%
Political Participation	7.4%
Gender Equality	19.8%
Freedom of Religion	0.3%
Safety and Security	6.0%
<i><u>Contested Public Values</u></i>	
Protection of Minority Interests	19.0%
Economic Opportunity	22.3%
Privacy	15.0%
Racial and Ethnic Diversity	33.9%
Women's Right to Terminate an Unwanted Pregnancy	27.5%
Gun Ownership	- 15.8%

For this study, public value deniers (n=61) were defined as anyone who supported seven or less of the value choice vignettes as public values. Table 8 provides an overview of the frequency of support for each public value within the public value denier group.

Table 8

Public Values for Public Value Deniers

Value	Supported	Percentage
Freedom of Speech	46	75.4%
Freedom of Religion	42	68.9%
Liberty	41	67.2%
Safety and Security	36	59.0%
Civil Rights	32	52.5%
Political Participation	32	52.5%
Gun Ownership	27	44.3%
Gender Equality	24	39.3%
Economic Opportunity	23	37.7%
Racial and Ethnic Diversity	22	36.1%
Access to Adequate Health Care	20	32.8%
Protection of Minority Interests	19	31.1%
Women's Prerogative to Terminate an Unwanted Pregnancy	16	26.2%
Privacy	12	19.7%
n = 61		

Table 9 compares and contrasts support and denial of gun ownership as a public value with support and denial of access to adequate health care as a public value.

Table 9

Support and Denial of Public Values Related to Gun Ownership and Access to Adequate Health Care

		Access to Adequate Health Care as a Public Value	
		Support	Deny
Gun Ownership as a Public Value	Support	1310 (52.2%)	291 (11.6%)
	Deny	822 (32.8%)	86 (3.4%)

Due to the dependent variable being dichotomous, several logistic and probit models were generated (Table 10). Respondents were then categorized into age-based

cohorts to increase variance and a probit was performed using robust standard errors (Table 11). The dependent variable was access to adequate health care as a public value, and the independent variables were consensual and contested public values. Various controls including income, gender, marital status, parental status, employment, education, political affiliation, parent education, U.S. born, and race were included in the model.

Table 10

*Logit and Probit Models: Probability That a Respondent Believes Health Care Is a**Public Value*

	1	2	3	4	5 Preferred Model
<i>Consensual Public Values</i>					
Freedom of Speech	0.528 (0.338)	0.527 (0.400)	0.299 (0.196)	0.300 (0.230)	0.283 (0.230)
Liberty	0.904*** (0.306)	0.904*** (0.338)	0.498*** (0.179)	0.498** (0.195)	0.489** (0.190)
Civil Rights	0.371 (0.261)	0.371 (0.294)	0.214 (0.153)	0.214 (0.171)	0.142 (0.167)
Political Participation	0.188 (0.228)	0.188 (0.243)	0.110 (0.131)	0.110 (0.141)	0.101 (0.138)
Freedom of Religion	- 0.557** (0.250)	- 0.557** (0.280)	- 0.265** (0.135)	- 0.265* (0.155)	- 0.256 (0.158)
Gender Equality	0.855*** (0.182)	0.855*** (0.197)	0.507*** (0.107)	0.507*** (0.117)	0.432*** (0.117)
Safety and Security	0.243 (0.192)	0.243 (0.199)	0.137 (0.109)	0.137 (0.113)	0.158 (0.113)
<i>Contested Public Values</i>					
Protection of Minority Interests	0.316** (0.160)	0.316* (0.176)	0.209** (0.092)	0.209** (0.102)	0.205** (0.102)
Economic Opportunity	0.877*** (0.151)	0.877*** (0.164)	0.502*** (0.087)	0.502*** (0.093)	0.497*** (0.095)
Privacy	0.438*** (0.151)	0.438*** (0.156)	0.247*** (0.085)	0.247*** (0.088)	0.294*** (0.090)
Racial and Ethnic Diversity	0.849*** (0.134)	0.849*** (0.139)	0.480*** (0.075)	0.480*** (0.077)	0.470*** (0.078)
Gun Ownership	- 0.639*** (0.147)	- 0.639*** (0.147)	- 0.350*** (0.079)	- 0.350*** (0.078)	- 0.229*** (0.082)
Women's Right to Terminate an Unwanted Pregnancy	0.738*** (0.131)	0.738*** (0.136)	0.402*** (0.072)	0.412*** (0.074)	0.274*** (0.078)

<u>Opinions</u>					
Denial of Health Benefits in Faith-Based Org.	---	---	---	---	-0.108*** (0.019)
Vaccinations Before Public School Enrollment	---	---	---	---	0.050*** (0.019)
<u>Control Variables</u>					
Age	- 0.010 (0.061)	- 0.010 (0.064)	-0.002 (0.033)	-0.002 (0.035)	0.014 (0.035)
Income	- 0.028 (0.025)	- 0.028 (0.025)	- 0.018 (0.014)	- 0.018 (0.014)	- 0.019 (0.014)
Gender	0.232* (0.125)	0.232* (0.135)	0.128* (0.069)	0.128* (0.074)	0.119 (0.074)
Marital Status	- 0.010 (0.039)	- 0.010 (0.039)	- 0.010 (0.021)	- 0.010 (0.021)	- 0.014 (0.021)
Parent	0.067 (0.171)	0.067 (0.170)	0.029 (0.093)	0.028 (0.091)	0.035 (0.094)
Employment	0.066* (0.039)	0.066 (0.040)	0.034* (0.021)	0.034 (0.021)	0.039* (0.021)
Education	- 0.082 (0.055)	- 0.082 (0.055)	- 0.042 (0.030)	- 0.042 (0.030)	- 0.055* (0.030)
Political Affiliation	0.087** (0.034)	0.087*** (0.033)	0.048*** (0.018)	0.048*** (0.018)	0.039** (0.018)
Parent Education	- 0.113** (0.057)	- 0.113** (0.057)	- 0.064** (0.031)	- 0.064** (0.031)	- 0.056* (0.031)
U.S. Born	0.003 (0.316)	0.003 (0.324)	0.026 (0.170)	0.026 (0.173)	-0.012 (0.174)
Race	- 0.093 (0.192)	- 0.093 (0.194)	- 0.052 (0.105)	- 0.052 (0.104)	- 0.061 (0.108)
White	- 0.174 (0.721)	- 0.174 (0.712)	- 0.090 (0.391)	- 0.090 (0.377)	- 0.129 (0.388)
Black	- 0.057 (0.589)	- 0.057 (0.582)	- 0.025 (0.317)	- 0.025 (0.307)	0.017 (0.315)
Latino	- 0.179 (0.249)	- 0.179 (0.267)	- 0.108 (0.137)	- 0.108 (0.143)	- 0.080 (0.148)
Asian	- 0.032 (0.195)	- 0.032 (0.102)	- 0.017 (0.097)	- 0.017 (0.046)	- 0.022 (0.051)
(Constant)	- 1.932* (1.095)	- 1.932* (1.117)	- 1.173* (0.602)	- 1.1173* (0.604)	- 0.833 (0.614)

Logit	Yes	Yes	No	No	No
Probit	No	No	Yes	Yes	Yes
Robust SE	No	Yes	No	Yes	Yes
McFadden's Pseudo R ²	0.193	0.193	0.197	0.197	0.221

***p< .01, **p< .05, *p< .10

Table 11

*Probit Models with Robust Standard Errors: Probability That a Respondent Believes**Health Care Is a Public Value*

	Age-Based Cohorts				
	18-24	25-34	35-44	45-54	55 & Older
<u>Consensual Public Values</u>					
Freedom of Speech	1.910** (0.944)	0.173 (0.288)	- 0.323 (0.947)	0.955 (0.764)	- 3.633*** (1.056)
Liberty	0.038 (0.648)	0.507* (0.269)	0.818 (0.688)	1.114* (0.657)	- 5.659*** (0.949)
Civil Rights	- 0.293 (0.638)	0.138 (0.262)	0.595* (0.342)	0.319 (0.545)	- 0.298 (0.674)
Political Participation	- 0.546 (0.446)	0.025 (0.209)	0.387 (0.292)	- 0.185 (0.491)	1.298** (0.591)
Freedom of Religion	- 0.990** (0.450)	- 0.181 (0.229)	- 0.430 (0.359)	0.233 (0.578)	- 0.421 (0.694)
Gender Equality	0.765* (0.400)	0.600*** (0.181)	0.269 (0.280)	0.496 (0.376)	1.214** (0.554)
Safety and Security	0.936** (0.406)	0.183 (0.149)	0.515** (0.247)	- 0.998 (0.703)	- 0.592 (0.741)
<u>Contested Public Values</u>					
Protection of Minority Interests	0.886*** (0.278)	0.062 (0.158)	0.270 (0.202)	0.188 (0.331)	0.168 (0.598)
Economic Opportunity	0.088 (0.296)	0.580*** (0.139)	0.264 (0.225)	0.929*** (0.337)	0.794** (0.396)
Privacy	0.444 (0.318)	0.176 (0.135)	0.328 (0.211)	0.109 (0.306)	0.260 (0.380)
Racial and Ethnic Diversity	0.351 (0.295)	0.493*** (0.117)	0.438** (0.173)	0.443* (0.255)	0.866** (0.365)
Gun Ownership	- 0.122 (0.240)	- 0.356*** (0.114)	- 0.530*** (0.200)	- 0.834*** (0.303)	0.161 (0.386)
Women's Right to Terminate an Unwanted Pregnancy	0.477* (0.245)	0.445*** (0.110)	0.253 (0.171)	0.703** (0.279)	1.051*** (0.388)

<u>Control Variables</u>					
Income	- 0.003 (0.039)	- 0.014 (0.022)	- 0.010 (0.030)	- 0.169*** (0.046)	0.028 (0.071)
Gender	0.303 (0.218)	0.147 (0.103)	0.366** (0.159)	0.050 (0.233)	- 0.193 (0.336)
Marital Status	0.074 (0.071)	- 0.002 (0.029)	- 0.004 (0.043)	- 0.262*** (0.082)	0.168 (0.113)
Parent	0.485 (0.424)	- 0.013 (0.140)	- 0.171 (0.186)	0.279 (0.260)	0.821** (0.391)
Employment	-0.012 (0.054)	0.067* (0.039)	0.045 (0.059)	0.074 (0.071)	0.056 (0.088)
Education	- 0.102 (0.092)	- 0.028 (0.046)	- 0.068 (0.070)	0.112 (0.114)	- 0.059 (0.163)
Political Affiliation	-0.064 (0.057)	0.043* (0.024)	0.030 (0.047)	0.113 (0.077)	0.232*** (0.084)
Parent Education	0.047 (0.102)	- 0.049 (0.046)	- 0.073 (0.074)	- 0.188* (0.106)	- 0.212 (0.152)
U.S. Born	0.964* (0.581)	0.047 (0.259)	- 0.420 (0.463)	0.347 (0.367)	- 0.791 (0.557)
Race	- 1.752*** (0.239)	0.023 (0.193)	- 0.423* (0.257)	0.832** (0.326)	- 1.859*** (0.572)
White	- 8.583*** (1.028)	- 0.051 (0.823)	- 1.025 (0.935)	1.971* (1.038)	- 4.292* (2.237)
Black	- 5.753*** (0.865)	- 0.131 (0.671)	- 0.737 (0.799)	1.259 (0.897)	- 3.438* (1.809)
Latino	- 0.439 (0.301)	- 0.021 (0.191)	0.688 (0.474)	- 0.979 (0.684)	3.750*** (1.111)
Asian	- 3.557*** (0.588)	- 0.075 (0.389)	0.039 (0.049)	- 0.129 (0.106)	-- --
(Constant)	6.889*** (2.020)	- 1.406 (1.112)	0.557 (1.485)	- 3.690* (1.961)	13.469*** (3.523)
McFadden's Pseudo R ²	0.293	0.191	0.208	0.392	0.534
n	307	1188	547	275	192

***p< .01, **p< .05, *p< .10

Table 12 is similar to table 11 with the exception of two additional health care opinions related to health benefits and vaccinations being included as independent variables.

Table 12

*Probit Models with Robust Standard Errors: Probability That a Respondent Believes**Health Care Is a Public Value with Added Health Opinions*

	Age-Based Cohorts				
	18-24	25-34	35-44	45-54	55 & Older
<u>Consensual Public Values</u>					
Freedom of Speech	1.974** (0.863)	0.161 (0.281)	- 0.311 (0.988)	0.785 (0.811)	- 3.546*** (1.177)
Liberty	0.043 (0.588)	0.485* (0.267)	0.804 (0.689)	1.252* (0.700)	- 7.531*** (1.331)
Civil Rights	- 0.593 (0.691)	0.049 (0.246)	0.543 (0.359)	0.507 (0.554)	- 0.559 (0.724)
Political Participation	- 0.645 (0.434)	- 0.022 (0.198)	0.453 (0.303)	- 0.215 (0.467)	1.878*** (0.674)
Freedom of Religion	- 0.953** (0.402)	- 0.159 (0.236)	- 0.422 (0.368)	0.124 (0.556)	- 0.846 (0.808)
Gender Equality	0.720* (0.422)	0.521*** (0.181)	0.260 (0.290)	0.365 (0.353)	1.017* (0.612)
Safety and Security	0.995** (0.403)	0.199 (0.152)	0.490** (0.249)	- 0.757 (0.731)	- 0.407 (0.801)
<u>Contested Public Values</u>					
Protection of Minority Interests	0.925*** (0.293)	0.056 (0.157)	0.210 (0.210)	0.179 (0.349)	0.694 (0.647)
Economic Opportunity	0.098 (0.328)	0.601*** (0.140)	0.260 (0.224)	0.885** (0.360)	1.168*** (0.437)
Privacy	0.552 (0.311)	0.197 (0.138)	0.361* (0.210)	0.169 (0.338)	0.393 (0.437)
Racial and Ethnic Diversity	0.328 (0.284)	0.475*** (0.118)	0.453** (0.182)	0.401 (0.269)	0.673 (0.449)
Gun Ownership	- 0.030 (0.244)	- 0.265** (0.118)	- 0.381* (0.221)	- 0.642* (0.335)	0.941* (0.482)
Women's Right to Terminate an Unwanted Pregnancy	0.351 (0.255)	0.315*** (0.117)	0.086 (0.191)	0.625** (0.297)	0.983** (0.442)

***p< .01, **p< .05, *p< .10

<u>Opinions</u>					
Denial of Health Benefits in Faith-Based Org.	-0.080 (0.065)	-0.103*** (0.028)	- 0.103** (0.044)	- 0.114* (0.069)	- 0.333*** (0.078)
Vaccinations Before Public School Enrollment	0.098 (0.081)	0.069** (0.027)	0.032 (0.044)	- 0.023 (0.065)	0.013 (0.101)
<u>Control Variables</u>					
Income	0.002 (0.038)	- 0.010 (0.023)	- 0.013 (0.031)	- 0.153*** (0.045)	0.045 (0.073)
Gender	0.336 (0.235)	0.104 (0.106)	0.350** (0.159)	0.019 (0.232)	- 0.185 (0.369)
Marital Status	0.060 (0.072)	- 0.001 (0.030)	- 0.009 (0.042)	- 0.276*** (0.088)	0.183 (0.141)
Parent	0.436 (0.456)	0.020 (0.144)	- 0.187 (0.187)	0.230 (0.250)	0.914* (0.510)
Employment	-0.018 (0.054)	0.070* (0.039)	0.061 (0.059)	0.078 (0.076)	0.085 (0.094)
Education	- 0.129 (0.089)	- 0.050 (0.046)	- 0.073 (0.071)	0.111 (0.117)	- 0.075 (0.158)
Political Affiliation	-0.082 (0.057)	0.036 (0.025)	0.030 (0.048)	0.121 (0.083)	0.216* (0.119)
Parent Education	0.019 (0.111)	- 0.036 (0.046)	- 0.074 (0.075)	- 0.179* (0.104)	- 0.168 (0.169)
U.S. Born	0.764 (0.615)	- 0.019 (0.259)	- 0.327 (0.477)	0.422 (0.381)	- 1.593* (0.838)
Race	- 1.825*** (0.274)	0.006 (0.196)	- 0.411 (0.269)	0.757** (0.333)	- 1.893** (0.760)
White	- 8.867*** (1.160)	- 0.590 (0.816)	- 1.059 (0.970)	1.734 (1.074)	- 4.165 (2.951)
Black	- 5.912*** (0.950)	- 0.038 (0.665)	- 0.715 (0.831)	1.082 (0.890)	- 3.067 (2.187)
Latino	- 0.501* (0.298)	- 0.007 (0.195)	0.697 (0.474)	- 0.930 (0.743)	3.586*** (1.302)
Asian	- 3.738*** (0.613)	- 0.030 (0.391)	0.021 (0.051)	- 0.094 (0.101)	-- --
(Constant)	7.655*** (2.021)	- 1.043 (1.111)	0.747 (1.529)	- 3.167 (1.926)	15.867*** (4.255)
McFadden's Pseudo R ²	0.312	0.217	0.226	0.405	0.597
n	307	1188	547	275	192

Table 13 replaces the dependent variable of access to adequate health care as a public value with gun ownership as a public value. Access to adequate health care was included as an independent variable. All other independent and control variables used for Table 12 were also used for Table 13.

Table 13

*Probit Models with Robust Standard Errors: Probability That a Respondent Believes**Gun Ownership Is a Public Value*

	Age-Based Cohorts				
	18-24	25-34	35-44	45-54	55 & Older
<u>Consensual Public Values</u>					
Freedom of Speech	1.014 (0.696)	0.272 (0.233)	0.747 (0.457)	1.327** (0.666)	6.612*** (0.595)
Liberty	- 0.192 (0.432)	0.175 (0.275)	0.532 (0.594)	1.480** (0.640)	2.827*** (0.871)
Civil Rights	0.355 (0.424)	- 0.469 (0.287)	- 0.280 (0.414)	- 1.025 (1.276)	- 0.087 (0.582)
Political Participation	0.748** (0.328)	0.312* (0.188)	0.273 (0.275)	- 0.685 (0.648)	- 0.325 (0.615)
Freedom of Religion	0.171 (0.320)	- 0.006 (0.161)	- 0.082 (0.243)	0.193 (0.441)	0.776 (0.705)
Gender Equality	- 0.393 (0.301)	- 0.131 (0.183)	0.403 (0.248)	- 0.458 (0.519)	- 0.490 (0.552)
Safety and Security	- 0.134 (0.407)	0.092 (0.135)	0.249 (0.240)	0.246 (0.363)	0.915*** (0.341)
<u>Contested Public Values</u>					
Protection of Minority Interests	0.441* (0.264)	- 0.048 (0.139)	0.148 (0.202)	0.424 (0.350)	0.117 (0.408)
Economic Opportunity	0.332 (0.269)	0.081 (0.123)	0.221 (0.209)	0.598* (0.340)	- 0.567* (0.344)
Privacy	0.063 (0.266)	0.294** (0.116)	0.326* (0.174)	- 0.195 (0.237)	0.388 (0.297)
Racial and Ethnic Diversity	- 0.518** (0.246)	- 0.201* (0.104)	- 0.565*** (0.153)	- 0.165 (0.206)	- 0.231 (0.290)
Access to Adequate Health Care	- 0.016 (0.267)	- 0.262** (0.132)	- 0.430* (0.255)	- 0.648* (0.354)	0.436 (0.379)
Women's Right to Terminate an Unwanted Pregnancy	- 0.081 (0.202)	0.210** (0.095)	0.338** (0.145)	- 0.409* (0.211)	- 0.049 (0.259)

***p< .01, **p< .05, *p< .10

<u>Opinions</u>					
Denial of Health Benefits in Faith-Based Org.	0.194*** (0.052)	0.108*** (0.023)	0.247*** (0.036)	0.230*** (0.050)	0.297*** (0.076)
Vaccinations Before Public School Enrollment	0.008 (0.049)	- 0.054** (0.022)	- 0.050 (0.034)	- 0.039 (0.052)	- 0.158 (0.098)
<u>Control Variables</u>					
Income	0.000 (0.039)	0.000 (0.017)	0.020 (0.023)	0.013 (0.037)	0.134** (0.057)
Gender	- 0.384** (0.180)	- 0.199** (0.081)	0.073 (0.120)	0.193 (0.189)	0.209 (0.258)
Marital Status	- 0.111 (0.072)	- 0.031 (0.022)	0.044 (0.035)	- 0.027 (0.063)	- 0.042 (0.098)
Parent	0.019 (0.354)	0.300*** (0.103)	0.230 (0.144)	- 0.178 (0.247)	0.225 (0.322)
Employment	- 0.056 (0.037)	- 0.011 (0.026)	- 0.047 (0.036)	0.018 (0.055)	- 0.074 (0.068)
Education	- 0.016 (0.080)	- 0.108*** (0.036)	- 0.110** (0.052)	- 0.014 (0.069)	- 0.206** (0.097)
Political Affiliation	- 0.048 (0.043)	- 0.067*** (0.020)	- 0.091*** (0.033)	- 0.125*** (0.048)	- 0.093 (0.067)
Parent Education	- 0.157* (0.080)	- 0.002 (0.035)	- 0.028 (0.053)	- 0.022 (0.080)	- 0.081 (0.115)
U.S. Born	0.663 (0.619)	0.274 (0.205)	- 0.692** (0.348)	0.549 (0.489)	0.474 (1.006)
Race	- 0.229 (0.294)	- 0.023 (0.130)	- 0.296 (0.210)	0.378 (0.384)	5.524*** (0.732)
White	- 1.150 (1.368)	- 0.211 (0.530)	- 0.585 (0.720)	1.396 (1.588)	22.787*** (3.306)
Black	- 1.346 (1.105)	- 0.270 (0.435)	- 0.437 (0.585)	1.025 (1.274)	17.279*** (2.671)
Latino	- 0.213 (0.273)	- 0.396*** (0.142)	0.761** (0.376)	- 1.174** (0.541)	0.038 (0.992)
Asian	- 0.171 (0.626)	- 0.366 (0.256)	0.152*** (0.056)	- 0.470 (0.848)	-- --
(Constant)	0.890 (2.196)	1.141 (0.842)	0.283 (1.244)	- 2.599 (2.547)	- 37.661*** (3.563)
McFadden's Pseudo R ²	0.171	0.104	0.176	0.255	0.354
n	307	1188	547	275	192

MODELS AND RESULTS

Of the 2,509 survey respondents, 1,686 identified either strongly or weakly with the Republican or Democratic party (Table 4). For those who identified as Democrat or Republican, a total of 1,452 (57.9%) supported access to adequate health care as a public value compared to 234 (9.3%) who denied it as a public value when comparing between all respondents. Solely among the 1,686 who identified as Republican and Democrat, 86.1% supported and 13.9% denied access to adequate health care as a public value.

600 individuals identified as strong or weak Republicans for approximately 23.9% of the respondent pool. Of the 600 Republicans compared to the total surveyed population, 436 (17.4%) supported access to adequate health care as a public value while 164 (6.5%) denied it as a public value. Solely among the 600 who identified as Republicans, 72.7% supported access to adequate health care as a public value compared to 27.3% who denied it as a public value.

Of all the respondents, 1,086 individuals identified as strong or weak Democrats making up approximately 43.3% of the population. Compared to the total surveyed population, 1,016 (40.5%) of the 1,086 Democrats supported access to adequate health care as a public value in contrast to the 70 Democrats (2.8%) who denied it as a public value. When comparing between the 1,086 Democrats, approximately 93.6% supported and 6.4% denied access to adequate health care as a public value.

A representative survey conducted by the Pew Research Center found that 60% of American's believe that health care coverage should be the responsibility of the government (Bialik, 2017). For all Republicans/leaning Republicans, 10% believed in a

single national government program, 20% believed in a mix of government and private programs, 56% didn't believe the government to be responsible but thought Medicare/Medicaid should continue, and 10% indicated there should be no government involvement of any kind (Bialik, 2017). Among all Democrats/leaning Democrats, 43% supported a single national government program, 38% believed in a mix of government and private programs, 12% thought Medicaid/Medicare should continue but the government is not responsible for health care coverage, and 0% indicated no government involvement at all (Bialik, 2017).

When comparing the Pew Research Center results (Bialik, 2017) to the 2016 Citizen Values Project, more Democrat and Republican respondents appear to support access to adequate health care as a public value (86.1%) to the belief that the government should be responsible for providing health coverage (60%). Although the 2016 Citizen Values Project is not a representative survey and is skewed towards Democrats, the framing of health care coverage (access to adequate vs. government is responsible) may explain the 26.1% differential regarding health care as a public value and government provided universal health coverage.

Differences between consensual and contested values can be found among those who support and deny access to adequate health care as a public value. Table 6 indicates that the original consensual and contested public values of all respondents are upheld for the supporters of access to adequate health care as a public value, but for the deniers of access to adequate health care as a public value, only three of the public values are consensual, eight are contested, and two (racial and ethnic diversity & women's right to terminate an unwanted pregnancy) aren't considered public values for this group. The

top public values that had the greatest percentage difference between deniers and supporters of access to adequate health care as a public value were all contested public values including racial and ethnic diversity (33.9%), women's right to terminate an unwanted pregnancy (27.5%), and economic opportunity (22.3%) (Table 7).

Individuals who supported seven or less of the value choice vignettes as public values were defined as public value deniers. The most supported public value among the 61 public value deniers was freedom of speech (75.4%) and the least supported was privacy (19.7%) (Table 8). Access to adequate health care was the fourth least supported public value at 32.8%.

The first two hypotheses pertain to gun ownership and access to adequate health care. Before addressing the hypotheses through quantitative analysis, an overview is provided of how all respondents to the 2016 Citizen Values Project categorize into the areas of support or denial for both gun ownership and access to adequate health care as a public value. Table 9 provides the number of respondents (n=2,509) and percentages of supporters or deniers for gun ownership and access to adequate health care as public values. A majority of respondents (52.2%) supported both gun ownership and access to adequate health care as a public value while only 3.4% denied both as public values (Table 9). For the remaining 44.4% who supported one but not the other, 32.8% supported access to adequate health care as a public value while denying gun ownership as a public value, and 11.6% supported gun ownership as a public value but denied access to adequate health care as a public value.

Table 10 shows the results of multiple logit and probit models. The probit model using robust standard errors with two questions related to opinions involving health care

initiatives was selected as the preferred model for this study. Public values such as liberty, gender equity, protection of minority interests, economic opportunity, privacy, racial and ethnic diversity, and women's rights to terminate a pregnancy are all significant and positively associated with the public value - access to adequate health care. The public value of gun ownership is significant and negatively associated with the public value of access to adequate health care. There is no significant association between access to adequate health care and the public values of freedom of speech, civil rights, public participation, freedom of religion, and safety and security. There is an increase in the predicted probability that citizens will support access to adequate health care as a public value if they believe that any of the following are also public values: liberty, gender equity, protection of minority interests, economic opportunity, privacy, racial and ethnic diversity, and women's rights to terminate a pregnancy. If gun ownership is considered a public value, then there is a decreased predicted probability that access to adequate health care will be supported as a public value.

Within the opinions portion of this research, the predicted probability of citizens supporting access to adequate health care as a public value decreases if they favored exempting faith-based organizations from providing certain health services required by the government. An increased predicted probability for supporting access to adequate health care as a public value was observed for citizens who favored requiring vaccinations of children before being allowed to enroll in public schools.

Using Bozeman's (2017) citizenship publicness theory and criteria developed for consensual and contested public values, supporting access to adequate health care as a public value was significantly associated with supporting only two consensual public

values (liberty ($p < .05$) and gender equity ($p < .01$)). In contrast, there was a strong and significant association ($p < .01$) between endorsing any of the six contested public values as a public value (protection of minority interests, economic opportunity, privacy, racial and ethnic diversity, gun ownership, and women's rights to terminate a pregnancy) and supporting access to adequate health care as a public value.

To increase the variance within the model, tables 11, 12, and 13 use five age-based cohorts including 18-24, 25-34, 35-44, 45-54, and 55 and older. The results of the probit regression models for health care as a public value without the inclusion of opinions (see table 11) and with the inclusion of opinions (see table 12) as independent variables are provided in the order of the hypotheses. The probit model results for gun ownership as a public value including opinions as independent variables are provided in table 13. Variance inflation factors were run for each model to test for multicollinearity resulting in VIF scores below 10 for all independent variables.

The results from table 11 and 12 partially support hypothesis 1 – that individuals who believe that gun ownership is a public value have a decreased predicted probability of believing access to adequate health care is a public value. The results from table 11 indicate strong and significant support ($p < .01$) for hypothesis 2 for three of the age groups (25-34, 35-44, and 45-54). The results from table 12 are mixed indicating significant support for ages 25-34 ($p < .05$) and ages 35-44 and 45-54 ($p < .10$) while those in the age group 55 and older are significant ($p < .10$) but refute the hypothesis.

The second hypothesis claimed that individuals who believe access to adequate health care is a public value have a decreased predicted probability of believing gun

ownership is a public value. In table 13, the results are supported and significant for ages 25-34 ($p < .05$) and ages 35-44 and 45-54 ($p < .10$).

Hypothesis 3 stated that individuals who believe that women's right to terminate an unwanted pregnancy is a public value have an increased predicted probability of believing access to adequate health care is a public value. This claim was broadly supported with results from table 11 indicating strong and significant support ($p < .01$) for ages 25-34 and 55 and older as well as significant support for ages 45-54 ($p < .05$) and ages 18-24 ($p < .10$). The results from table 12 also demonstrate strong and significant support ($p < .01$) for hypothesis 3 for the age group 25-34 as well as significant support ($p < .05$) for ages 45-54 and 55 and older.

Results from table 11 and 12 indicate partial support for the fourth hypothesis – individuals who believe that racial and ethnic diversity is a public value have an increased predicted probability of believing access to adequate health care is a public value. Table 11 shows support for hypothesis 4 from all age groups with the exception of one including 25-34 ($p < .01$), 35-44 and 55 and older ($p < .05$), and 45-54 ($p < .10$). The results from table 12 indicate significant support for the fourth hypothesis among the age groups 25-34 ($p < .01$) and 35-44 ($p < .05$).

The fifth hypothesis posited that individuals who support enacted public values related to health care initiatives (i.e. vaccines and not denying health benefits at a faith based organization) have an increased predicted probability of supporting health care as a public value. The results from table 12 partially support hypothesis 5 for age groups 25-34 and 55 and older ($p < .01$), 35-44 ($p < .05$), and 45-54 ($p < .10$) within the denial of health benefits opinion and only ages 25-34 ($p < .05$) within the vaccination opinion.

Hypothesis 6 asserted that individuals who deny enacted public values related to health care initiatives (i.e. no vaccines and denial of health benefits at a faith based organization) have an increased predicted probability of supporting gun ownership as a public value. The results from table 13 indicate strong and significant support ($p < .01$) for the sixth hypothesis across all five age ranges within the denial of health benefits opinion. Significant support for hypothesis 6 within the vaccination opinion was only observed in ages 25-34 ($p < .05$).

Respondents were provided a listing of the following fourteen public values and asked to sacrifice one of them: liberty, freedom of speech, civil rights, public participation, freedom of religion, safety and security, gender equity, protection of minority interests, economic opportunity, privacy, racial and ethnic diversity, gun ownership, access to adequate health care, and women's rights to terminate a pregnancy. Hypothesis 7 stated that the value that citizens are most willing to self-sacrifice will be a contested public value, and the value that citizens are least willing to self-sacrifice will be a consensual public value.

Although access to adequate health care is a contested public value among the U.S. citizens surveyed, it was the least self-sacrificed value out of the fourteen public values. Table 3 provides the results for the values sacrifice scenario. A total of only seven citizens (.28% of respondents) selected to sacrifice access to adequate health care. More respondents chose to sacrifice their liberty or civil rights compared to those that sacrificed access to adequate health care. Freedom of religion has been identified as a consensual public value; however, the results in table 3 spotlight freedom of religion as the greatest self-sacrificed value for all surveyed respondents at 41.7% compared to all

other contested and consensual public values. Based on this analysis, hypothesis 7 is refuted and not supported since the value that citizens were most willing to self-sacrifice was a consensual public value, and the value that they were least willing to self-sacrifice was a contested public value. The following section theorizes why this anomaly may have occurred.

PUBLIC VALUES DISSONANCE

Within social psychology, when two items of information like behavior, feelings, opinions, or ideas don't align psychologically, they are said to be in a dissonant relationship (Festinger, 1962). Cognitive dissonance is a "theory that centers around the idea that if a person knows various things that are not psychologically consistent with one another, he will, in a variety of ways, try to make them more consistent" (Festinger, 1962, p. 10). In reviewing the results from the values sacrifice scenario, several candidate public values are at odds between what individuals value for themselves compared to what individuals value for all citizens in their society. To describe this phenomenon, the term public values dissonance was created and can be defined as "when a group of citizens highly values a specific individualized right or benefit but does not believe that the same right or benefit should be available or provided to all citizens of a society or vice versa." Access to adequate health care and freedom of religion both serve as examples of public values dissonance when comparing self-sacrificed public values to consensual and contested public values for society.

There are many factors that may help explain this anomaly including supply and demand, economics, self-interest, and how these values have been framed or incorporated into a society including foundational documents, citizen revolt, war, or the creation of

new national systems. For example, a study exploring partisanship, self-interest, and racial resentment as it relates to health care opinion in the U.S. found that self-interest played a major role in moderating individual opinions about universal health insurance (Henderson & Hillygus, 2011). The study noted that if a Republican was personally worried about their own medical expenses, then they were less likely to switch to oppose universal health coverage even as other Republicans grew more negative towards universal health insurance (Henderson & Hillygus, 2011).

DISCUSSION AND CONCLUSION

This analysis focuses on health care as a public value and how it relates to other potential public values. The significant and positive relationships between access to adequate health care and other contested public values could serve as a springboard for future comparative studies of public values on a global scale. Citizens from countries that have universal health coverage may indicate access to adequate health care as a consensual public value. Countries with universal health coverage may have access to adequate health care embedded in foundational documents or indicated in landmark speeches or court decisions like Article 43 of Spain's constitution which recognizes the right to health protection for its citizens (Spanish Const. art. 43).

There are limitation to this study. With nearly all social science research including this study, omitted variable bias is a threat to the internal validity due to it being a non-randomized field study. Selection bias is also another threat to internal validity due to the survey excluding anyone younger than 18. In addition, selection bias towards younger adults (who might be more technologically savvy) or those who have access to a computer and the internet is a possibility since MTurk is an internet based

survey system that pays respondents to answer surveys. Another limitation of this study is that it only surveyed citizens who reside in the U.S. Finally, the U.S. health care system is not representative for other countries.

To continue exploring public value sacrificing, a new measure could be explored by asking respondents to not only sacrifice one value for themselves but to also sacrifice one value for society. This has the potential to address the self-interest likely resulting within the values self-sacrifice exercise. It would allow for a deeper exploration of the consensual and contested public values identified through the anchored candidate public value statements. In conclusion, future research involving access to adequate health care should explore at minimum four countries with each representing one of the four various health care delivery models: Bismarck, Beveridge, National Health Insurance, and Out-of-Pocket. Comparative public values on an international scale may yield new insights into the similarities and differences of the public values held by citizens from differing cultures and societies. This type of comparative international research may eventually lead to a better understanding of global public values with the potential of creating a global public values inventory.

CHAPTER 3

ESSAY 2: PROPERTY RIGHTS AND POLICYMAKING FOR THE HUMAN BODY: GENOMIC PIRACY, PRIVACY, AND PROPERTY

Do you own your DNA or the genetic information within it? Within the United States, the answer depends on the state in which you reside. Former President Barack Obama weighed in on this debate when discussing the Precision Medicine Initiative when he said, “I would like to think that if somebody does a test on me or my genes, that that’s mine, but that’s not always how we define these issues” (Davis, 2016). Debates regarding ownership of organs, tissues, blood, and genes are not new and neither are concerns related to the protection and ownership of personal genetic information by individuals (Daley & Cranley, 2016; Evans, 2016; Karrow, 2016; Kish & Topol, 2015; Lash, 2015; Rao, 2007; Annas, 1999; Colonna, 1998; Murray, 1997; Lin, 1996; Annas, Glantz, & Roche, 1995; Barrad, 1992; ASHG Ad Hoc Committee on DNA technology, 1988).

An individual’s genome is comprised of DNA which is both a molecule and a medium for storage and transmission of genetic information. Genetic information specifies the production of proteins and nucleic acids that affect biology, including the propensity to develop diseases. DNA and the genetic information it contains are unique for several reasons. DNA sequence data can be used as an identifier; can provide insight into an individual’s future health; can be used to stigmatize, marginalize, and victimize individuals; reveals personal information about an individual and his or her genetic inheritance; and can be directly linked to an individual’s parents, children, relatives, and ancestors (Annas, 1995).

DNA has been described as a “future diary” (Annas & Elias, 1992), because the information within the genetic code describes aspects of an individual’s future health (Annas, 1995). The term “genetic exceptionalism” describes the “claim that genetic information is sufficiently different from other kinds of health-related information that it deserves special protection or other exceptional measures” (Murray, 1997, p. 61). In many contexts, analysts oppose genetic exceptionalism because genetic information is not sufficiently different from other health or ancestry information to warrant special treatment (Gostin & Hodge, 1999). For many purposes, genetic information can be treated as similar to other health information. Genetic exceptionalism is introduced to demonstrate a debate that has been occurring for over two decades regarding the uniqueness of genetic information while simultaneously preparing readers at the conclusion of this study to ask themselves: “Is my DNA sequence more unique than my other health-related information” and “should there be specific protections in place for my DNA?”

“Gene piracy” describes the sometimes but not always surreptitious bio-prospecting of remote areas and their populations (McGirk, 1998); but what constitutes genetic piracy? Genetic piracy, also known as DNA theft, is a controversial and loaded term. Is genetic piracy only the unauthorized collection or analysis of an individual’s genetic information without their expressed consent or can it also describe the unauthorized secondary use of an individual’s genetic information? For the purpose of this paper, genetic piracy is the unauthorized collection, secondary use, or analysis of an individual’s genetic information without explicit consent. With the proliferation of new technology and DNA testing services, non-consensual genetic testing on ‘stolen’ DNA is

more feasible (“Genetic Privacy,” 2009). Several legal cases explore the nuances of genetic piracy.

The proposed Genetic Privacy and Nondiscrimination Act of 1995 set out to create uniform rules throughout the U.S. to protect the individual privacy of genetic information. Specifically, the Genetic Privacy Act addressed concerns regarding genetic prophecy, genetic discrimination, and the use of an individual’s genetic information to divulge information about relatives (Murray, 1997; Annas, Glantz, & Roche, 1995). A proposed 1996 Senate bill, the Genetic Confidentiality and Nondiscrimination Act of 1996 attempted to give individuals property rights over their own DNA samples but was never enacted into law (Gostin & Hodge, 1999). State legislatures began enacting their own laws to protect individuals’ genetic information due to the lack of comprehensive federal legislation (Rothstein, 2008). An inconsistent patchwork of state laws now exists related to genetic information, genetic privacy, and genetic property.

The concept of genetic data ownership is complex and evolving. Many individuals assume that their genetic data is their own personal property; however, federal law does not grant individuals exclusive property rights to their genetic information. Five states (Alaska, Colorado, Florida, Georgia, and Louisiana) currently recognize genetic information as the property of the individual from whom it came, and four additional states (Alabama, Massachusetts, South Dakota, and Texas) have introduced bills seeking to grant property rights to genetic information (Roberts, 2017).

GENETIC POLICIES AND LAWS

GENETIC NONDISCRIMINATION LAWS

The Genetic Information Nondiscrimination Act (GINA) and the Patient Protection and Affordable Care Act (ACA) are two federal policies that protect citizens from genetic discrimination. GINA was debated by Congress for nearly thirteen years before being signed into law in May 2008 (Roberts, 2011). GINA is often cited as an example of proactive policymaking, because it was enacted before genetic testing became as common as it has become (Green, Lautenbach, & McGuire, 2015) and before there was evidence of widespread genetic discrimination (Roberts, 2010). Prior to GINA, only three federal cases involved genetic discrimination (Roberts, 2010). During 1998 in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, prospective employees of Lawrence Berkley Laboratory were screened for various medical conditions including pregnancy, sickle cell trait, and syphilis (Norman-Bloodsaw, 1998; Roberts, 2010). Employees filed a discrimination claim that eventually reached the Ninth Circuit (Roberts, 2010). The Ninth Circuit affirmed the ADA claim but reversed the Title VII (part of the Civil Rights Act that prohibits employment discrimination) as well as the state and federal privacy claims (Norman-Bloodsaw, 1998). In 1999, the plaintiffs in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* received a settlement (MacLean, 1999). In 2002, the Burlington Northern, Santa Fe Railroad Corporation settled with its union after workers who had filed Workers Compensation claims for carpal tunnel syndrome learned that the Railroad performed unauthorized genetic testing (Hudson, 2002). As part of the settlement, Burlington Northern paid 36 employees a total of \$2.2 M and promised to lobby Congress to enact legislation that prevented genetic discrimination in the workplace (Girion, 2002; Hudson, 2002). A third case involved an insurance broker employee, Terri Sergeant, who was dismissed from her job due to the

cost of the medication to treat her alpha-1 antitrypsin deficiency (Roberts, 2010; Clayton, 2003; Silvers & Stein, 2002). The Equal Employment Opportunity Commission (EEOC) supported her ADA claim and issued a permission-to-sue letter (Silvers & Stein, 2002).

Between GINA's enactment in 2008 until 2014, approximately 1,400 genetic discrimination claims were submitted to the EEOC (Bowers & Hutcheson, 2016). Of those, approximately 245 claims yielded successful outcomes for the employees totaling \$4.48M in damages (Bowers & Hutcheson, 2016). In 2015, in *Lowe v. Atlas Logistics Group Retail Services, Atlanta, LLC* (2015), two men were awarded damages totaling \$2.25 M due to their employer violating GINA when the employer illegally requested and required both men to provide genetic information via cheek swab to determine the employee who was defecating in the company's warehouse. Some critics consider GINA too narrow, because it fails to address genetic discrimination in long-term care, disability, or life insurance (Green, Lautenbach, & McGuire, 2015).

The ACA was signed into law by then-President Obama on March 23, 2010. The ACA provides protection to citizens by prohibiting health insurers from discriminating due to preexisting conditions or onset of an illness (Blumenthal, Abrams, & Nuzum, 2015). Discrimination due to the identification of preexisting conditions from genetic test results is also prohibited under the ACA (Green, Lautenbach, & McGuire, 2015).

GENETIC PRIVACY LAWS

Privacy is the ability of an individual or group to safeguard information about themselves, and the right to privacy is the ability for an individual or group to limit and control the disclosure of information about themselves (Moore, 2000). The importance of protecting health privacy within the United States led to the 1996 Health Insurance

Portability and Accountability Act (HIPAA) and the addition of the 2003 Privacy Rule under HIPAA (Rothstein, 2008). In 2013, HIPAA was modified to include genetic information as health information in order to prevent health insurers from using it to set premiums, determine benefits, or decide eligibility for health insurance (National Human Genome Research Institute, 2017). Although HIPAA offers a floor of protection at the federal level by identifying genetic information as protected health information (Baruch & Hudson, 2008), existing federal laws offer only weak protection for genetic privacy (Rothstein, 2008).

Several proposals for federal genomic privacy laws have been floated in the past. The Genetic Privacy and Nondiscrimination Act of 1995 and the Genetic Confidentiality and Nondiscrimination Act of 1996 both failed to be enacted as laws (Green, Lautenbach, & McGuire, 2015; Everett, 2003). Due to the lack of comprehensive federal legislation, many states began enacting their own legislation to ensure genetic privacy and prevent genetic discrimination (Everett, 2003; Annas, Glantz, & Roche, 1995; Rothenberg, 1995). Since the proposed federal genomic privacy laws failed and most “practice of medicine” issues are governed at the state level, genomic privacy became a state matter.

State laws concerning genetic privacy are disparate. Some states, e.g. Alabama, have no state law. Five states (Alaska, Colorado, Florida, Georgia, and Louisiana) grant property rights to the individual being tested (National Human Genome Research Institute, 2018; Ray, 2017; Gutmann et. al., 2012). Legislative bills have been introduced in four states (Alabama, Massachusetts, South Dakota, and Texas) to grant property rights to an individual for their genetic information (Roberts, 2017). Other states, e.g. Arizona, prevent genetic discrimination for life and disability insurance (A.R.S. § 20-

448). Muddled state laws led President Obama’s Presidential Commission for the Study of Bioethical Issues to recommend a consistent baseline of privacy protections at the state and federal government levels for whole genome sequence information (Gutmann et. al., 2012). Present-day genetic privacy concerns echo sentiments from over two decades ago that “current legal safeguards are inadequate, fragmented, and inconsistent, and contain major gaps in coverage” (Gostin, 1995, p. 324).

VARIATIONS IN STATE PRACTICES

In other legal domains, incongruent policies among states have been addressed by enacting relatively consistent state laws, based on model statutes. The U.S. President’s Commission for the Study of Ethical Problems in Medicine, Biomedical, and Behavioral Research (1981) produced a report that proposed a Uniform Determination of Death Act (UDDA). Some states lacked statutes for death and those with statutes had different definitions and provisions that confounded the legal determination of death (Abram, 1981). This became important when organ transplantation and other advances in medical technology made the determination of death a practical problems with real consequences for both donors and for those awaiting organs for transplantation. How does one determine biological death or when is it legal to extract a donated liver, cornea, or kidney? (Abram, 1981). A uniform law for all states on the determination of death was proposed by the Uniform Law Commissioners in 1980 (Abram, 1981). A model statute was adopted by most states and territories, bringing more consistency in how death was determined throughout the U.S. (Abram, 1981). As of 2018, the Uniform Law Commission (2018) identified fourteen states that had not yet adopted the UDDA as state law. This example illustrates how the uniform state laws approach does not ensure a

completely consistent national policy, because states are allowed to reject, modify, or accept and enact the recommended uniform law. The model statute approach does, however, enable progress toward consistency among jurisdictions.

The U.S. medicolegal death investigation system is an example of disparate state practices that might benefit from national standards. Some states have medical examiners, who are usually trained medical professionals; other states have only coroners, who are typically elected officials, or a mixture of both coroners and medical examiners (National Research Council, 2009). The National Research Council (2009) recommended the creation of state medical examiner systems to replace and eliminate existing coroner systems.

Federal law prohibiting the sale of human organs is another example of federal policy imposing consistency and reducing uncertainty. In 1983, Dr. H. Barry Jacobs established a company in Virginia to procure and sell kidneys from healthy individuals (Denise, 1985). The estimated cost for a single kidney purchased through an organ broker was up to \$10,000 (Rohter, 2004). Virginia quickly enacted legislation to prevent the selling of human organs, and several other states followed suit (Denise, 1985). On October 19, 1984, the National Organ Transplant Act (PL 98-507) was signed into law. It included a ban on the sale of human organs (Mueller, 1988; National Organ Transplant Act, 1984). The radical threat of human organ commercialization led Congress to prohibit the commodification of human organs (Mueller, 1988).

Federal laws like HIPAA can be used to set a floor at the national level with states having the ability to raise the ceiling to provide additional protections. The three examples of the uniform determination of death, the medicolegal death investigation

system, and the prohibition on the sale of human organs are models for how uniformity can be imposed through the recommendation and implementations of model statutes, uniform federal standards, and federal laws.

DNA AND GENETIC INFORMATION AS PROPERTY

State legislative approaches involving genetic information began in the 1970's due to concerns about genetic discrimination. During the 1970's, North Carolina and Florida enacted legislation to prevent health insurance discrimination related to sickle cell trait or hemoglobin C trait (Rothenberg, 1995). Concerns about the use of genetic information in underwriting insurance led several additional states to implement statewide policies involving genetic information as property during the 1990's (Rothenberg, 1995). As federal bills, such as the Genetic Privacy and Nondiscrimination Act of 1995 and the Genetic Confidentiality and Nondiscrimination Act of 1996 failed to become law, state laws defining genetic information as property were passed by five states from 1990-2004 with an additional four states introducing similar legislation from 2012-2017 (Roberts, 2017). Currently, Alaska, Colorado, Florida, Georgia, and Louisiana grant property rights to the individual being tested (National Human Genome Research Institute, 2018). Table 14 summarizes those state statutes.

Table 14

State Laws Conferring Property Rights to Individuals and Their Genetic Information

State	Year	State Statute	Defined property right	Acts covered and penalties
Alaska	2004	AS §18.13.010 – 18.13.030	DNA samples and the results of DNA analysis are the exclusive property of	A person may bring a civil action against a person who collects a DNA sample from the person, performs a

			the person sampled or analyzed.	<p>DNA analysis on a sample, retains a DNA sample or the results of a DNA analysis, or discloses the results of a DNA analysis in violation of this chapter. In addition to the actual damages suffered by the person, a person violating this chapter shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, \$100,000.</p> <p>Unlawful DNA collection, analysis, retention, or disclosure is a class A misdemeanor.</p>
Colorado	1994	CRS §10-3-1104.7	<p>Genetic information is the unique property of the individual to whom the information pertains.</p> <p>Release of genetic information that identifies the person tested for purposes other than diagnosis, treatment and therapy requires specific written consent. Exemptions under the law include some uses by research facilities.</p>	<p>Any individual who is injured by the violation of an entity may seek the following remedies:</p> <p>The greater of:</p> <p>(I) Actual damages suffered by the individual.</p> <p>(II) \$10,000</p> <p>Attorney fees and costs of action may also be recovered by the prevailing party.</p>

Florida	1992	FS §760.40	DNA analysis may be performed only with the informed consent of the person to be tested, and the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested.	A person who violates paragraph (a) is guilty of a misdemeanor of the first degree, punishable as provided in s. 775.082 or s. 775.083 .
Georgia	1995	OCGA §§33-54-1	Genetic information is the unique property of the individual tested.	<p>The use and availability of information concerning an individual obtained through the use of genetic testing techniques may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual tested.</p> <p>Penalties include unfair trade practice and subjected to the “Fair Business Practices Act of 1975”.</p> <p>Actual damages suffered by the individual.</p> <p>Attorney fees and costs of action may also be recovered by the prevailing party.</p>

Louisiana	1997	LA Rev Stat § 22:1023	<p>(1) An insured's or enrollee's genetic information is the property of the insured or enrollee. No person shall retain an insured's or enrollee's genetic information without first obtaining authorization from the insured, enrollee, or their representative.</p> <p>(2) Any person who either:</p> <p>(a) Through a request, the use of persuasion, under threat, or with a promise of reward, willfully induces another to collect, store, or analyze a DNA sample.</p> <p>(b) Willfully collects, stores, or analyzes a DNA sample in violation of this Section, or willfully discloses genetic information in violation of this Section, shall be liable to the individual for each such violation.</p>	<p>(1i) Actual damages sustained as a result of the collection, storage, analysis, or disclosure, or \$50,000, whichever is greater.</p> <p>(1ii) Treble damages, in any case where such a violation resulted in profit or monetary gain.</p> <p>(1iii) Attorney fees and costs of action may also be recovered by the prevailing party.</p> <p>(2i) Any actual damages sustained as a result of the collection, analysis, or disclosure, or \$100,000, whichever is greater.</p> <p>(2ii) Attorney fees and costs of action may also be recovered by the prevailing party</p>
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THE HUMAN BODY AS PROPERTY

A tissue sample can be defined as a material that serves as a source of DNA including body fluids, blood, tissues, and organs (Clayton et. al., 1995). These types of specimens haven't always been conceptualized by the public as sources of DNA which could be used for biomedical research without their knowledge or permission. In fact, the

admittedly incomplete case law about biospecimens has awarded property rights to academic institutions or medical centers that house them.

Several ethical and legal cases address the human body as property and can be categorized into two types of scenarios: unauthorized secondary use or unauthorized collection or sharing of an individual's genetic information. Cases that reside in the unauthorized secondary use category include *Henrietta Lacks*, *Moore v. Regents of the University of California*, *Greenberg v. Miami Children's Hospital Research Institute, Inc.*, *Washington University v. Catalona*, and *Tilousi v. Arizona State University*. Two ongoing and unresolved cases (*Cole v. Gene by Gene Ltd.* and *Peerenboom v. Perlmutter*) comprise the other scenario of unauthorized collection or sharing of an individual's genetic information. These cases demonstrate how research institutions and legal systems have shaped the interpretation and understanding of property rights concerning the human body.

A rich history of cases and decisions regarding unauthorized secondary use exists. One of the most publicized cases involves Henrietta Lacks, her family, and Johns Hopkins University. In 1951, in an era before the doctrine of "informed consent" was fully integrated into research practices, Johns Hopkins University acquired and used cervical cancer cells from Henrietta Lacks to create the first immortal cell line known as the HeLa cell line (Skloot, 2010). Lacks was not told about those uses of her cells, and her family learned about it only when re-contacted years later (Skloot, 2010). HeLa cells became essential tools in a multi-million dollar industry. Although neither Lacks nor her family received any compensation (Skloot, 2010), Johns Hopkins University recently announced that a building will be named in honor of Henrietta Lacks, and two members

of the Lacks family have sat on a National Institutes of Health (NIH) panel for the past five years to review applications requesting access to the genomic information found in HeLa cells (Brown, 2018). The extraordinary case of Henrietta Lacks has ignited public debate and raised awareness for the need to develop robust policies concerning informed consent and biospecimens (Beskow, 2016).

Moore v. Regents of the University of California is another case based on a cell line derived from removal of cancerous tissue. John Moore underwent treatment for hairy-cell leukemia and eventual removal of his spleen at the University of California at Los Angeles Medical Center (Moore, 1990). David Golde and other UCLA researchers created and patented a cell line known as the Mo cell line from Moore's spleen cells and sold the cell line to Genetics Institute for \$330,000.00 and 75,000 shares of stock (Drabiak-Syed, 2010; Moore, 1990). They also informed Moore that his blood could potentially be sold to researchers for \$10,000.00 per liter (Truog, Kesselheim, & Joffe, 2012). The case progressed to the California Supreme Court which ruled that Moore had no property rights over his extracted cells or the medical discoveries developed using his cells (Contreras, 2016; Rao, 2007; Moore, 1990). However, the court determined that Moore's physician failed to obtain informed consent and breached his fiduciary duty to Moore as a patient (Contreras, 2016; Rao, 2007; Moore, 1990).

Greenberg v. Miami Children's Hospital Research Institute, Inc. is another property case concerning the use of patented genetic diagnostics for Canavan Disease. The Greenbergs were Chicago parents who had children with Canavan disease (Greenberg, 2003). They formed a Canavan disease registry and database and joined with collaborating institutions to enable the study of this debilitating disease of childhood

(Greenberg, 2003). The Greenbergs also enticed Dr. Reuben Matalon to conduct research on Canavan disease, using the samples and patient network they provided (Greenberg, 2003). Through his research, Dr. Matalon discovered and isolated the gene mutated in Canavan disease (Greenberg, 2003). Without telling the family or other collaborators, he patented the discovery and assigned rights to his research institution, Miami Children's Hospital (Colaiani et. al., 2010; Greenberg, 2003). Once the patent was awarded, Miami Children's Hospital hired an inexperienced licensing agency to pursue an aggressive campaign of restrictive licensing practices which imposed diagnostic limitations, including on the very organizations that had enabled the discovery (Colaiani et. al., 2010). This caused mistrust, frustration, and anger among patients and advocates who helped with the initial discovery (Colaiani et. al., 2010). Litigation ensued and eventually led to a 2003 settlement which was sealed (Colaiani et. al., 2010; Greenberg, 2003). The litigation did not challenge the patent directly, but rather alleged breach of informed consent, misappropriation of biological materials, conversion, and unjust enrichment by Miami Children's Hospital at the expense of its collaborators. While the settlement remains sealed, the public statement accompanying the settlement indicates that it constrains the hospital's licensing framework, especially for nonprofit testing services such as those involved in discovering the Canavan-associated gene, and permits medical research without a license (Colaiani et. al., 2010; Greenberg, 2003).

The next case involves Dr. William Catalona who conducted prostate cancer research that involved collecting thousands of patient samples. The prostate cancer tumor samples were stored in the Biorepository of Washington University in St. Louis (Washington University, 2007). Dr. Catalona eventually left Washington University and

encouraged his patients and those who had contributed to the Biorepository to provide permission to transfer samples to his new employer, Northwestern University (Washington University, 2007). In *Washington University v. Catalona*, the U.S. Court of Appeals, Eighth Circuit, held that the Washington University owned the biological samples housed in their Biorepository because those were the terms of the initial donation, and that the patients as well as Dr. Catalona were not authorized to transfer property rights from Washington University to another institution (Washington University, 2007; Rao, 2007).

In the 1990s, a group of researchers led by Therese Ann Markow at Arizona State University (ASU) collected DNA samples from the Havasupai Tribe in order to study diabetes; however, unbeknownst to the tribe, the DNA samples were distributed to various researchers and used for purposes other than diabetes research (Reardon & TallBear, 2012; Garrison, 2013). The uses were discovered only because a member of the tribe, Carletta Tilousi, was invited to Daniel Garrigan's dissertation defense where research findings using the Havasupai blood samples were presented (Drabiak-Syed, 2010). The secondary use of Havasupai DNA samples included studies of inbreeding (Markow & Martin, 1993) and schizophrenia (Markow et. al., 1993). Other studies focused on migration patterns in human populations, the topic of the graduate student's dissertation, which challenged the tribal origin story (Dalton, 2004). Once the Havasupai learned of these unauthorized uses of their samples, the tribe and ASU commissioned Stephen Hart, an attorney, to investigate the incident (Drabiak-Syed, 2010). The Hart report documented how the scientists acted as if they had property rights over the Havasupai's blood once it was collected (Reardon & TallBear, 2012; Hart & Sobraske,

2003). In *Tilousi v. Arizona State University* (2005), the tribe filed a lawsuit against ASU and the Arizona Board of Regents. The case ultimately settled with the Board of Regents agreeing to return all of the blood samples to the Havasupai, to provide other forms of assistance to the tribe including scholarships, and to pay 41 tribal members a total of \$700,000.00 (Garrison, 2013; Reardon & TallBear, 2012; Harmon, 2010).

The term “genetic piracy” was used to describe the actions of the researchers and institutions who used the samples without permission from the Havasupai tribe (Allen, 2010). The uses beyond the initial informed consent for diabetes research bred distrust and long-term negative consequences for the Havasupai, for research, for the researchers, and for the research institutions involved (Pacheco et. al., 2013; Couzin-Frankel, 2010). The case is widely known, and often cited as “group harm” and breach of investigator responsibility to participants in research. ASU was held accountable for violating the rights of research participants when fully transparent informed consent practices were disregarded.

Although these cases are not precedential, a theme emerges indicating that property interests for genetic data do not exist for individuals who contribute their DNA or whose DNA is discarded (Roberts, 2017). Instead, decisions about property rights of the human body have favored the academic institutions or medical centers that collect, store, develop, research, and patent discoveries from biospecimens obtained from patients. The denial of individual property rights for donated or surgically extracted biospecimens has been supported and upheld by federal courts, but a recent movement to redefine data ownership seeks to empower individuals, limit exploitation, create a market

for health information, protect family members, and better the common good of society (Contreras, 2016).

Two current cases involve unauthorized collection or sharing of an individual's genetic information, and they have the potential to shape the landscape of property and privacy rights involving individual genomic information. Both cases involve states that have granted property rights to individuals for their genomic information. In *Cole v. Gene by Gene Ltd.* (2018, 2017), Michael Cole sued Gene by Gene Ltd., which is the parent company of Family Tree DNA, for violating Alaska's Genetic Privacy Act by publishing his results without his consent (Graf, 2017). After receiving a lot of email spam, Cole searched for his email address on the internet and found his genetic test results were published and available to the public (Cole, 2017; Roberts, 2017). A federal judge denied Gene by Gene's motion for summary judgement which claimed that Alaska's Genetic Privacy Act is unconstitutional (Graf, 2017). In August 2018, the United States Court of Appeals for the Ninth Circuit affirmed the district court's decision to deny class action certification (Cole, 2018). The case now returns to the district court and is still pending (Cole, 2018).

Peerenboom v. Perlmutter involves the theft of DNA during a lawsuit deposition in the state of Florida (Angrist, 2018). Florida grants exclusive property rights of DNA results to the person whose DNA was analyzed (Fla. Stat. Ann. § 760.40(2)(a)) (Genetic testing, 1992). A neighborhood dispute between Isaac and Laura Perlmutter and Harold Peerenboom escalated to include a hate mail campaign about Harold Peerenboom (Peerenboom, 2017). In an attempt to prove that the Perlmutter were behind the hate mail campaign, Peerenboom conspired with his attorney, William Douberley, to collect

the Perlmutter's DNA from objects they touched during the deposition including a water bottle and specially designed DNA binding paper (Peerenboom, 2017). The Perlmutter's sued Peerenboom, Doublerly, and the lab that processed their DNA claiming conversion, because their DNA was collected surreptitiously and fraudulently (Angrist, 2018; Peerenboom, 2017). The case of *Peerenboom v. Perlmutter* is pending and will be another step in determining the implications of state laws that create an individual property right in genetic information.

THE VALUE OF MATERIALS FROM THE HUMAN BODY

How much is material from the human body worth? The process of commodifying the body and the construction of DNA as property is highly contested (Everett, 2003). Determinations of the value of materials from the human body can be categorized into three subtypes: recompense for harm, amount estimated or paid for samples or access to samples, and proposed or imposed civil penalties for violating a law.

The monetary value of either settlements or damages awarded is listed in the aforementioned cases regarding recompense for harm. In addition to those cases, several other examples demonstrate the growing marketization and monetization of genetic information. At the 10th International Congress of Human Genetics in Vienna, Austria, Bear (2001) suggested that research subjects be compensated for access to their DNA for at least \$50,000.00, royalties from any profits, or a combination of the two. Genentech recently reached a \$60 M deal with 23andMe, a direct-to-consumer (DTC) genetic testing company, to generate whole genome sequencing information of 3,000 participants who have Parkinson's disease or are first-degree relatives of someone who has Parkinson's disease (Herper, 2015). The Genentech deal provides 23andMe \$10 M upfront with the

potential of an additional \$50 M for meeting milestones (Leuty, 2015). For Nebula Genomics, George Church considered the possible monetization of an individual's genome at \$500.00 for access to specific information of interest per interested company (Cohen, 2018). Several companies provide compensation to individuals who are eligible and participate in research including DNAsimple, Genos, LunaDNA, and EncrypGen. DNAsimple compensates individuals \$50.00 each time they qualify for a study and submit a saliva sample ("DNAsimple," 2018) while Genos' compensation ranges from \$50.00 - \$250.00 for participation in their Research Beta program ("Genos," 2018). LunaDNA proposes to issue shares of ownership in the company for people who join and contribute their DNA and health data ("LunaDNA," 2018) while EncrypGen allows individuals to earn DNA tokens when they share their genomic information via blockchain ("EncrypGen," 2018). Table 15 summarizes the value of materials from the human body.

Table 15

Examples of Values for Materials from the Human Body

Case or Example	Type	Action	Value
Organ Brokers	Estimated value	Selling a single kidney	Up to \$10,000.00
<i>Moore v. Regents of the University of California</i>	Estimated value	Price quote to patient	\$10,000.00 per liter of blood
<i>Moore v. Regents of the University of California</i>	Recompense for harm	Physician sold cell line	\$330,000.00 75,000 shares of stock
<i>Norman-Bloodsaw v. Lawrence Berkeley Laboratory</i>	Recompense for harm	Settlement	\$2.2 M to 7 employees
Burlington Northern, Santa Fe Railroad Corporation	Recompense for harm	ADA Violation	\$2.2 M to 36 employees
<i>Tilousi v. Arizona State University</i>	Recompense for harm	Settlement	\$700,000 to 41 members of the Havasupai tribe
<i>Lowe v. Atlas Logistics Group Retail Services, Atlanta, LLC</i>	Recompense for harm	GINA Violation	\$2.25 M to 2 employees
J.C. Bear	Estimated value for access to genetic information	Paper presented at 10 th International Congress of Human Genetics in Vienna, Austria	At least \$50,000.00 for access to each research subject's genetic information, royalties from any profits, or a combination of the two
George Church and Nebula Genomics	Estimated value for access to genetic information	Access to certain information of a patient's genome	\$500.00 for access per company
23andMe	Payment for access to genetic information	Sold access to Parkinson's samples to Genentech	\$10 M initially for access to 3,000 participant's DNA Up to additional \$50 M for achieving milestones

			Up to \$60 M total for access to 3,000 participant's DNA
DNAsimple	Payment for access to genetic information	Access to an individual's genomic information	\$50.00 for each saliva sample submitted per qualified study
Genos	Payment for access to genetic information	Access to an individual's genomic information	\$50.00 - \$250.00 for participation in the Research Beta
LunaDNA	Payment for access to genetic information	Access to an individual's genomic and health information	Shares of ownership in the company
EncrypGen	Payment for access to genetic information	Access to an individual's genomic information via blockchain	DNA tokens
Alaska Genetic Privacy Act of 2004	Proposed civil penalties	Civil penalties	\$5,000.00 for compensation to the victim \$100,000.00 if the violation afforded the violator monetary gain or profit
Colorado	Proposed civil penalties	Civil penalties	The greater of: (I) Actual damages suffered by the individual. (II) \$10,000 Attorney fees and costs of action may also be recovered by the prevailing party.
Georgia	Proposed civil penalties	Civil penalties	Actual damages suffered by the individual.

			Attorney fees and costs of action may also be recovered by the prevailing party.
Louisiana	Proposed civil penalties	Civil penalties	<p>(1i) Actual damages sustained as a result of the collection, storage, analysis, or disclosure, or \$50,000, whichever is greater.</p> <p>(1ii) Treble damages, in any case where such a violation resulted in profit or monetary gain.</p> <p>(1iii) Attorney fees and costs of action may also be recovered by the prevailing party.</p> <p>(2i) Any actual damages sustained as a result of the collection, analysis, or disclosure, or \$100,000, whichever is greater.</p> <p>(2ii) Attorney fees and costs of action may also be recovered by the prevailing party</p>

GENETIC HACKING, ANONYMITY, AND RE-IDENTIFICATION

DNA is a unique identifier, and genetic information contained in the genome is unique to each individual (McGuire & Gibbs, 2006a, 2006b). Even monozygotic twins' genomes aren't exactly identical (Bruder et. al., 2008). Prior to the completion of the Human Genome Project, Clayton et. al. (1995) anticipated the possibility of anonymous DNA samples having their anonymity compromised. The potential risk of using genetic databases to link anonymous DNA sequences back to identified individuals was also

anticipated (Sweeney, 1997; National Human Genome Research Institute, 1996). Lin et al. (2004) illustrated the ability to identify an individual with only 75 single-nucleotide polymorphisms (SNPs). In 2005, a teenage boy tracked down and found his anonymous sperm donor “father” by using a commercial genetic database service, Family Tree DNA, and other online resources (Stein, 2005). Wendy Kramer, founder of Donor Sibling Registry, also used Family Tree DNA and the Internet to find her daughter’s anonymous sperm donor (Lehmann-Haupt, 2010). Family histories are also being rewritten by DTC genetic testing companies like 23andMe and Ancestry.com that provide ancestry results and sometimes reveal family secrets including infidelity or adoption (Kolataaug, 2017). Aldhous and Reilly (2009) demonstrated how an individual (Aldhous) had his genome hacked by his co-author (Reilly) who amplified Aldhous’ DNA from a drinking glass and had it analyzed with few roadblocks. The successful hacking of Aldhous’s genome was chronicled in detail to demonstrate vulnerabilities in the system, raise awareness about the potential for genome hacking, and advocate for laws to protect the privacy of an individual’s genomic information (Aldhous & Reilly, 2009). The hacking of 300,000 email/usernames and passwords from Ancestry’s RootsWeb server as well as the ninety-two million usernames and passwords stolen from MyHeritage illustrates another form of genetic hacking (Wong, 2018; Blackham, 2017).

Green and Annas (2008) imagined the collection and analysis of DNA from presidential candidates to assess genetic risks, indicate ethnic background, or expose potential health problems of political opponents. In October 2018, Senator Elizabeth Warren from Massachusetts used a DNA test in an attempt to bolster her claims that she is of Native American descent (Perrigo, 2018). Tribal leaders within the Cherokee Nation

and other indigenous communities expressed frustration because citizenship and cultural lineage are determined by sovereign tribal groups and not DNA testing (Horton, 2018).

Anonymity can no longer be assured in studies involving genomic testing (Korf, 2013), and yet “individuals have an autonomy-based right to determine with whom they want to share their DNA data” (McGuire & Beskow, 2010, p. 371). In a study of 30 participants who underwent genomic sequencing through two NIH research protocols, several individuals asserted the importance of confidentiality as a form of control that is inherently a human right (Jamal et. al., 2014). As the capability to re-identify the source of de-identified DNA samples increases, solutions to strengthen and streamline laws should be considered to govern whole-genome sequence data collection, protect against privacy breaches, and ensure accountability for violations that involve unauthorized use of an individual’s genetic information (“Genetic privacy,” 2013; Gutmann, 2013; Gutmann & Wagner, 2013).

Inconsistent federal policies regarding the interpretation of DNA identifiability produces confusion for patients, researchers, and policymakers (McGuire, 2008). Ethical, legal, and social implications abound regarding the use of DTC genetic testing along with third party services like private or public recreational genomic databases to identify individuals or their descendants. The ability to identify anonymous individuals using genomic data has grown significantly in a short time (Schadt, Woo, & Hao, 2012; Im et. al., 2012; Homer et. al., 2008). Gymrek et. al. (2013) demonstrated the ability to identify anonymous research subjects through the use of recreational genetic databases and Y chromosome short tandem repeats (Y-STRs). “Molecular photofitting” is a developing technique that utilizes DNA to predict phenotypes, and it has resulted in

guiding some law enforcement agencies to suspects while leading to at least one confession by a murderer after seeing his sketched composite from DNA left at the crime scene (DeFrancesco, 2018; Miller, 2017).

Another technique known as “long-range familial searching” has gained notoriety after the capture of the alleged Golden State Killer. The Golden State Killer is presumed responsible for the rape of more than fifty victims and the murder of at least twelve victims within the state of California between 1976 to 1986 (Arango, 2018). The use of DNA and genealogy to solve the cold case known as the “Bear Brook Murders” led detectives to use the same type of technique for the Golden State Killer (Arango, 2018). DNA from the rape and murder of Charlene and Lyman Smith had been sitting in a freezer since 1980 until detectives had the DNA converted into a format that could be uploaded into GEDmatch, a public database for DNA and genealogical research (Jouvenal, 2018). The analysis from GEDmatch returned several distant relatives of the killer, likened to third cousins, which allowed detectives to form twenty-five family trees (Jouvenal, 2018). Through census information, obituaries, news clippings, gravesite locators, LexisNexis, websites, and police databases, the detectives identified great-great-great grandparents who were common ancestors between the distant cousins and the killer (Jouvenal, 2018). Investigators narrowed the potential suspects down to Joseph James DeAngelo and another man due to their age and having resided in similar locations as the killer (Jouvenal, 2018). DNA from a dirty tissue found in Joseph James DeAngelo’s trash led authorities to arrest and charge him with multiple counts of murder (Harrison & Osborne, 2018). His case is pending.

The practice of long-range familial DNA searching within forensic databases like the U.S. National DNA Index System (NDIS), which is part of the Combined DNA Index System (CODIS), is controversial with ten states allowing for it while two states, Maryland and Washington D.C., have banned the practice. (Jouvenal et.al., 2018). At least thirteen criminal cases from April to August 2018 (mostly cold cases but one as recent as April 2018) have reported using long-range familial searches to solve cases (Erlich et. al., 2018). Through the use of identity-by-descent (IBD) segments of genetic relatives as well as the analysis of 1.28 million individuals who used DTC consumer genomics, Erlich et. al. (2018) predict that a match of a third cousin or closer relative will occur for approximately 60% of long-range familial searches using individuals of European descent. Erlich et. al. (2018) also used an individual from the 1000 Genomes Project to demonstrate that re-identification of human subjects through long-range familial searching is possible.

PRIVACY CONCERNS

The potential for invasions of genetic privacy continues to increase as technological advances involving genomics rapidly expand. DNA is unlike a credit card whose number can be changed after fraudulent activity; it is a permanent identifier, and can be used in various ways including direct linkage to family members, forensic cases, discrimination, and providing information about an individual's health (Roche & Annas, 2006; Annas, 1995). Concerns about violations of genetic privacy and property rights have led some to call for a federal genetic privacy law (Roche & Annas, 2006).

A survey of 13,000 individuals about their attitudes toward consent and data-sharing in biobank-based research revealed that 90% deemed health information privacy

important to them while 64% indicated that the privacy of their health information worried them (Sanderson et. al., 2017). In the same study, the most highly endorsed statement (at 86%) was related to information needed about biobanking governance which stated “I would want to know what would happen if a researcher misused the health information in the biobank” (Sanderson et. al., 2017, p. 7). Public trust is essential for participation in research and without proper privacy protections, the public’s trust could dwindle and slow the pace of or otherwise compromise research (McGuire & Gibbs, 2006b).

Due to the availability and use of DTC genetic testing, the public has become increasingly aware of and protective about how their DNA and genomic information is stored and used (Lewis et. al., 2012). Class action lawsuits have been filed in Minnesota and Texas by parents which led to the destruction of 5.3 million residual dried blood samples in Texas alone (Javitt, 2013; Lewis et. al., 2012). These cases illustrate the drastic consequences that can occur when consent is not obtained and the perspectives of individuals who contribute their biospecimens are overlooked (Javitt, 2013).

There are also growing concerns from experts about personal privacy and the use of nonforensic genealogical databases to conduct forensic searches for criminal suspects. Few legal barriers exist that limit law enforcement from conducting criminal searches with nonforensic genetic databases (Ram, Guerrini, & McGuire, 2018). Ethical and legal concerns about long-range familial searches include threats to collective civil liberties, government genetic surveillance, and the use of relatives to identify suspects who never voluntarily shared their genetic information within a nonforensic database (Ram, Guerrini, & McGuire, 2018). Some companies like 23andMe will not share customer

information unless legally compelled by the law while other companies like GEDmatch explicitly allow for information housed within their database to be searched by law enforcement agencies investigating sexual assault or homicide (Ram, Guerrini, & McGuire, 2018; Jouvenal et.al., 2018). Some scholars have even argued that someone who is a relative of an individual within CODIS has more genetic privacy rights than if that person was a relative of someone in GEDmatch (Molteni, 2018). Due to ethical and legal concerns as well as inconsistent laws governing nonforensic database searches by law enforcement, policies are needed to protect citizens from undue genetic searches without a relevant and reasonable cause. Recommended policies include a Stored Genetics Act, setting prerequisites that must be met prior to conducting long-range familial searches, and defining genome-wide information as identifiable private information through the U.S. Department of Health and Human Services (Erlich et. al., 2018; Ram, Guerrini, & McGuire, 2018). A politician in the Maryland House of Delegates is proposing a bill to restrict the use of nonforensic database searches in criminal investigations within Maryland while four states (California, Colorado, Texas, and Virginia) have implemented protocols regulating access and use of nonforensic databases for long-range familial searching (Jones, 2019).

Protecting genetic privacy by defining genetic information as property is a contested idea that has been debated for more than twenty-five years (Allen, 1997). Several scholars have advocated making genetic information the property of an individual (Annas, 1999; Colonna, 1998; Lin, 1996; Barrad, 1992; ASHG Ad Hoc Committee on DNA technology, 1988). Recent works also support individuals having rights to their genetic data (Daley & Cranley, 2016; Evans, 2016; Karrow, 2016; Kish &

Topol, 2015; Lash, 2015). Others have argued that individuals should not be granted property rights to their genetic information. One major argument against property rights for genetic information relates to concerns that individuals could restrict access and subsequently chill research (Miller, 1968). Another argument posits that “the term ‘property’ connotes control within the marketplace and therefore protects economic interests in genetic information” (Suter, 2004, p. 746).

Personal genetic ownership can be viewed as a bundle of limited property entitlements that include the right to access, the right to commercialize, and the right to exclude (Roberts, 2017). Exploring progressive property theory for genetic information has been suggested since it acknowledges the lived human experience while not limiting itself strictly to costs and benefits (Roberts, 2017).

Laws often lag behind technological developments. The technological advances within genomic sciences over the past five years including the ability to identify anonymized individuals via Y-STRs or IBD segments of genetic relatives signals the need for new genomic policies to protect citizens. As the medical information commons develops, as sequencing costs decline, and more companies pay consumers for access to their genetic information, greater protections for individual genetic information is necessary. The following section proposes a menu of national policy options to bolster the protections for individuals and their genetic information while reducing uncertainty, variability, and inconsistency from state to state.

NATIONAL POLICY RECOMMENDATIONS FOR GENETIC PROPERTY, PIRACY, AND PRIVACY

Technological advances coupled with an increase in direct-to-consumer genetic testing, clinical genetic testing, and large-scale biomedical research programs like the Precision Medicine Initiative's All of Us program will only increase the potential for breaches of privacy. Over 17 million people have participated in DTC autosomal DNA testing as of September 2018 (Larkin, 2018). The ability to re-identify de-identified personal genomes and the potential for genetic surveillance of citizens through the use of nonforensic databases have serious ethical, legal, and social implications. The first recommendation calls for a national policy to protect the privacy of participants who have donated their genomic information in de-identified form to scientific research. The recommendation also calls to protect the privacy of citizens from undue genetic searches without relevant and reasonable cause. Finally, the recommendation calls for the establishment of national guidelines to outline criteria that must be met to satisfy relevant and reasonable cause for law enforcement to legally compel nonforensic databases to assist in criminal investigations for heinous crimes like murder or sexual assault.

POLICY RECOMMENDATION 1 – GENETIC PRIVACY POLICY

The unauthorized re-identification of an individual using their de-identified genetic information is strictly prohibited unless re-identification could lessen or prevent a serious and imminent threat to the health and safety of the individual or others. Furthermore, the use of nonforensic databases for the identification of suspects as part of a criminal investigation is strictly prohibited unless a threshold is met within established national guidelines for relevant and reasonable cause. If relevant and reasonable cause criteria are met, companies owning nonforensic databases can be legally compelled by

the law to assist law enforcement agencies in criminal investigations involving sexual assault or homicide.

For the second recommendation, genetic piracy refers to the unauthorized collection, secondary use, or analysis of an individual's genetic information without their expressed consent. With recent examples of genetic theft in *Peerenboom v. Perlmutter* and the hacking of 300,000 email/usernames and passwords from Ancestry's RootsWeb server, genetic piracy concerns will only continue to proliferate (Angrist, 2018; Blackham, 2017). As technology accelerates and the cost to sequence the human genome decreases, this paper calls for a national policy to proactively prevent genetic piracy in the future.

POLICY RECOMMENDATION 2 – GENETIC ANTI-PIRACY POLICY

The unauthorized acquisition, collection, storage, access, analysis, disclosure, surreptitious use, or reproduction of an individual's genetic information is strictly prohibited.

Florida passed its law granting property rights to individuals for their genetic information in 1992 (Rothenberg, 1995). A quarter-century later, individual state laws concerning genetic information as individual property are inconsistent. Individuals already have the right to commercialize their DNA through several companies (see Table 15). The use of consent documents in DTC genetic testing companies, medical centers, and academic institutions to grant access to genetic information of an individual or the ability of individuals to control access to their genetic information on a case-by-case basis at other companies illustrates that right to access already exists. Finally, the right to exclude others from using genetic information is evident in the blood spot lawsuits in

Texas and Minnesota which resulted in the destruction of millions of newborn baby blood samples. Over 42 million individuals within the U.S. already have some form of property right in their genetic information when accounting for the five states who already have established property laws for genetic information (see Table 14). This recommendation calls for a national policy to alleviate the confusion that exists from state to state regarding property rights for DNA samples, individual genetic information, and the results of DNA analysis.

POLICY RECOMMENDATION 3 – GENETIC PROPERTY POLICY

DNA samples, genetic information, and the results of DNA analysis are the exclusive property of the person sampled or analyzed.

The FBI Anti-Piracy Warning states that a fine of \$250,000.00 and up to five years in prison could result for criminal copyright infringement (FBI Intellectual Property Theft/Piracy, 2018). Although unauthorized reproduction or distribution of copyrighted materials is not the same as genetic piracy, the establishment of civil and criminal penalties for the theft of a form of property could help to establish a foundation for considering penalties for these policies. Using select penalties from the five states who have existent genetic information property rights can also serve as a foundation.

Recommended penalties for violating any of the three proposed policy recommendations are a Class A Misdemeanor and compensation of at least \$10,000.00 and no more than \$100,000.00 per violation.

DISCUSSION AND CONCLUSION

Moving from policy recommendations to policy implementation will take political action. Policy implementation requires a sponsor in the House of

Representatives or the Senate who will advocate and champion the bill through the following process: the bill is sent to committee; the committee studies and decides if the bill should be released for a vote; the bill is voted upon and must pass both the house and the senate with a majority, then the bill has ten days to be signed into law or vetoed by the President (USAGov, 2019). This is the most straightforward path for policy recommendations to follow in order to become law, but the path does not mention the many potential competing interests, obstacles, or delays that the recommendation could face including other national priorities and policies, timing, lobbyists who work for organizations that are against the proposed policy, activist groups, other members of the House of Representatives or the Senate, and the President's agenda just to name a few.

Prophylactic genetic legislation has not always been successful, and it took thirteen years for GINA to finally become a law. A major purpose for enacting GINA was to alleviate the public's concern that their genetic test results could be used against them. At the same time, GINA protected the public from discrimination while encouraging them to participate in new genetic technologies, research, and testing (Areheart & Roberts, 2019). GINA could have been drafted as a privacy or a property law but instead Congress selected GINA to be an antidiscrimination statute (Roberts, 2011). GINA does not provide individuals with any property rights in their genetic information nor does it provide authority to individuals in deciding how their genetic information is used (Roberts, 2011).

The challenges that the proposed policy recommendations could face prior to and during the implementation process are both old and emerging. For over two decades, defining who owns genetic information has been controversial and fiercely debated

(Roberts, 2017). Although many people presume ownership of their DNA, there are no widespread legal property rights granted to individuals for their DNA (Roberts, 2017). Most recently in *Cole* and *Peerenboom*, courts have looked past previous precedence in *Moore* and *Greenberg* by allowing claims of conversion to move forward (Roberts, 2017).

Over the same period of time, biotech companies, researchers, and scholars have claimed that broad protections of an individual's genetic information or providing individuals rights to their genetic information could ultimately stymie research (Roberts, 2017). The genetic material contained within biospecimens is of high value both commercially and scientifically, and participants in research are starting to advocate for control, access, and compensation – a term known as “biorights” (Roberts, 2017; Daley & Cranley, 2016).

Within the privacy space, a major development which makes the recommended privacy policy more relevant than ever is the announcement made by Family Tree DNA that it is working with the FBI on cold cases by allowing agents to search its database of more than a million DNA profiles (Hernandez, 2019). From genealogists to law professors, sentiments after hearing the news ranged from feelings that consumer trust had been violated to comparing it to the creation of a national de-facto DNA database (Hernandez, 2019). A bill in Maryland, sponsored by Delegate Charles Sydnor, seeks to prohibit the use of DTC genetic testing databases to solve crimes (Barnes, 2019). Advocates for this paper's recommended privacy policy will likely cite the Fourth Amendment to the U.S. Constitution as a major reason for seeking to enact this policy

into law while opponents will likely focus on claims of justice as well as supporting law enforcement in solving violent crimes by any means necessary.

If there are two driving forces that accelerate the likelihood of these policy recommendations eventually becoming enacted into law, they would be the increasing value placed on information and the rapid development of new scientific technologies in genomics including identification of individuals through long-range familial DNA searching. As scandals like Cambridge Analytica or the hacking of Presidential elections using social media increase, the public is becoming more aware of how their information is both valuable and should be protected from abuse and manipulation. The same process will likely occur within genomics. Examples in this article show that genetic hacking of databases and the use of public DTC genetic databases by the FBI are already occurring and will likely grow as the technology rapidly develops. To pitch this bundle of genomic policy recommendations, it may help to formulate a name that would resonate with individuals while providing some context to the proposed policies. An idea is to name the proposed bundle of genomic policy recommendations “The Lacks’ Law: Policies to protect citizens’ genomic privacy, prevent genomic piracy, and establish their genetic information as their property.”

CHAPTER 4

ESSAY 3: SOCIO-TECHNICAL FUTURES OF OUR LIFESPAN: A SCENARIO

EXPLORING THE FUTURE OF LIFE UNTIL DEATH

The eugenic past has much to teach about how to avoid repeating its mistakes - not to mention its sins. But what bedeviled our forebears will not necessarily vex us, certainly not in the same ways. In human genetics as in so many other areas of life, the flow of history compels us to think and act anew - not about eugenics but about the control of human genetic information by geneticists, the media, insurers, employers, and government (Kevles, 2003, p. 317).

Futures studies encourage the development of imaginaries and the design of new knowledge systems through various methods including but not limited to scenarios, forecasting, foresight, and prediction. The creation of multiple futures is promoted through the strategic thought processes fostered by various types of scenarios and scenario planning (Amer, Daim, & Jetter, 2013; Börjeson et. al., 2006). Fruitful outcomes in futures studies can materialize when scenario planning and design intersect with one another (Selin, Kimbell, Ramirez, & Bhatti, 2015). Futures studies can also utilize actor network approach, sociotechnical imaginaries, and anticipatory governance when attempting to create future scenarios. Actor network approach asserts that institutions, organizations, people, and even artifacts design and negotiate socio-technical systems (Latour, 1992). Sociotechnical imaginaries are visions of desirable futures through “collectively imagined forms of social life and social order reflected in the design and fulfillment of nation-specific scientific and/or technological projects” (Jasanoff & Kim, 2009, p. 120). Anticipatory governance encourages the responsible development of

emerging knowledge-based technologies throughout the development process through foresight, engagement, and integration (Guston, 2014; Barben, Fisher, Selin, & Guston, 2008).

Imaginarities involving genomics are not new to futures studies, and personalized medicine has been conceptualized as a sociotechnical imaginary of modern biomedicine (Tarkkala, Helén, & Snell, 2018). Many people place stock into the possible power of genetic prediction due to its promise for the discovery of their own predisposition to disease (Nelkin & Tancredi, 1989). Both desirable and undesirable futures involving emerging technologies like genomics or precision medicine enable choices to be explored and allow insight into potential problems to be extrapolated (Miller & Bennett, 2008). Futures studies and predictions of genetics and genomics have examined the advantages, challenges, and limitations of genetic susceptibility testing (Stemerding, Swierstra, & Boenink, 2010), global genetic carrier testing (Beaudet, 2015), next-generation sequencing (NGS) (Pillar, Isakov, & Shomron, 2014), whole-genome sequencing (WGS) in the general population (Lindor, Thibodeau, & Burke, 2017), and genomic sequencing of newborns at birth (Leach, 2009). Scenario development involving the future of medical diagnostics (Selin, 2008) illustrates how exposure to “the coproduction of scientific and technological artifacts...can cause scientists and engineers to, upon reflection, alter the agendas and strategic vision of science-in-the-making” (Guston, 2014, p. 229). This study seeks to design socio-technical futures involving precision medicine through the development of a complex scenario employing a socio-technical system for documenting human lifespans within the United States using actor network approach, sociotechnical imaginaries, and anticipatory governance.

PRECISION MEDICINE

In 2011, the National Academies published a report entitled “Towards Precision Medicine” in which the feasibility of restructuring the taxonomy of human disease through the use of molecular biology was explored. During the 2015 State of the Union address, President Obama called for the Precision Medicine Initiative in order to yield precision medicine’s promise – “delivering the right treatment at the right time - every time - to the right person” (Jackson, 2015). The two main components of the initiative include an immediate focus on cancer and a long-term approach to better understand human health and disease by generating new knowledge and knowledge systems (Collins & Varmus, 2015). Three of the most important future objectives for precision medicine are to 1) securely and ethically acquire, process, store, and network massive amounts of patient information (genetic, medical history, wearables, environmental factors) in order to extrapolate commonalities and dissimilarities among individuals and subpopulations to yield better individualized treatments; 2) attempt to reduce complexity while embracing uncertainty in order to improve individual health by using multiple forms of medical information to elucidate risk factors, nudge behaviors, and predict undesirable outcomes through preventative measures or future treatments, and 3) increase the legibility of diseases or disease states in order to improve clinical decision making and treatments by incorporating individual patient values.

LIFESPAN – A SOCIO-TECHNICAL FUTURE

The development of a future technology called *Lifespan* will be explored along with the socio-technical future it creates and the governance necessary for its implementation. The design and development of *Lifespan* reconceptualizes biomedical

research, patient engagement, insurance, laws, biobanks, drug development, the health care delivery system, and how the human lifespan is documented. *Lifespan* is intended to be a national system developed, deployed, and regulated by the U.S. government through agencies, national associations, and laws including but not limited to the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the Department of Health and Human Services (HHS), the U.S. Preventive Services Task Force, the Centers for Medicare and Medicaid Services (CMS), the American College of Medical Genetics and Genomics (ACMG), the American Medical Association (AMA), the U.S. Equal Employment Opportunity Commission (EEOC), the U.S. Department of Justice through the Americans with Disabilities Act (ADA), the Health Insurance Portability and Accountability Act of 1996 (HIPPA), the Genetic Information Nondiscrimination Act of 2008 (GINA), the American Hospital Association (AHA), and the AARP. The altruism of enrolling in *Lifespan* honors and rewards patients by providing incentives including robust health insurance, reduced drug costs, and opportunities for joining clinical trials for their particular disease or the benefit of others. The system has the potential to profoundly and positively affect the economy, human health, morbidity, mortality, and the national workforce.

DOCUMENTING LIFE TO DEATH

This scenario introduces the socio-technical system, *Lifespan*, with enrollment occurring at birth and ending at death. Anyone can elect to enroll or unenroll in the program at any given time. Informed consent is obtained from parents before they elect to enroll their child into *Lifespan* at birth. By enrolling their newborn, the newborn undergoes standard newborn screening where the heel is pricked and blood is collected,

stored on a Guthrie card, and sent to a lab for whole-genome sequencing. The newborn's profile is created within *Lifespan*, the whole-genome sequence is uploaded and stored within a secure national databank, and newborn screening for various diseases is initiated. Paternity testing for newborns is also conducted upon enrollment by either accessing the parent's or parents' DNA in the system or acquiring it directly from them.

By being enrolled in *Lifespan* the newborn is automatically covered by a national health insurance system that has stipulations to be met for continuous enrollment including routine check-ups for newborns, vaccinations, and annual physicals. The insurance system is supported by the Centers for Medicare and Medicaid Services, insurance companies, and businesses that participate in employer provided insurance. The establishment of the insurance is through federal law and prohibits all forms of discrimination based on genetic test results. Enrollees are provided medical treatment, long-term care insurance, long-term disability insurance, and life insurance as long as they remain in the program and follow established criteria. The goal would be for enrollees to experience significantly reduced premiums, co-pays, drug costs, medical expenses, and access to experimental drugs or treatments compared to having insurance from external insurers with less coverage, decreased benefits, and much higher rates.

Recommendations for Preventive Pediatric Health Care established by the American Academy of Pediatrics (AAP) will set standards of care that encourage continuity of care from newborns to adolescents until they reach twenty-one years of age. To remain enrolled in *Lifespan*, parents must adhere to the standards set by the AAP. Newborns will undergo well-child visits in order to ensure they are healthy, thriving, and meeting milestones. Well-child visits include measurements, physical examinations,

vaccinations, bloodwork, and obtaining results from whole-genome sequencing through the pediatrician and a genetic counselor. Once results are shared with parents, they are provided access to their child's *Lifespan* account and dashboards which will be continuously updated with new information throughout the child's life including genetic, biomedical, social, and environmental information. Results indicating potential genetic diseases or predispositions will allow parents to experience anticipatory guidance from experts, proactively prepare for the child's medical needs, learn dosage response and drug interactions for an array of medications, understand risks for increased susceptibility, join disease support groups and coalitions, and receive notifications for all clinical trials involving their child's disease or predisposition.

Annual physical exams and screenings will become standard at five years of age until death. Physicals will include physical examination, bloodwork, measurements, and an overall assessment using *Lifespan*. Wearable device information that has been uploaded over the year will allow a real-time snapshot for clinicians to discuss health and wellness, physical exercise, exposure to environmental risks, and any abnormalities that may appear. The patient's whole-genome will be sequenced annually and updated in the system. In addition, screening the patient's blood using liquid biopsies would allow for proactive screening, early detection, and prevention. Results from blood screening would also be uploaded into *Lifespan*. All results combined will allow the clinician to proactively educate patients about increased susceptibility and ways to avoid risk through behavior modification, diet, and environmental exposure.

Patient literacy and knowledge about disease states will experience a paradigm shift as patients move from understanding disease as a binary system to understanding

disease as a continuum influenced by genetics, the environment, and social factors. Through patient input into the system, ways of effectively communicating risk will be identified and implemented. The identification of patients who experience success with behavior modification or lifestyle change based on susceptibility results can aid in the development of new methods for interventions.

Lifespan is a secure national databank that collects, stores, analyzes, and networks patient information. Electronic medical records will be required to be interoperable with *Lifespan* in order for patient information to be made seamlessly available for clinicians, pharmacies, clinics, and hospitals. The design and implementation of a data sharing platform for research utilizing either a gatekeeper model or an open-access model could benefit the community greatly (Bertagnolli, et. al., 2017). The use of blockchain in *Lifespan* may also be implemented in order to allow for user controlled portable identity, the maintenance of patient information exchanges and transactions over time, and the storage of individual patient medical assets. The governance of patient information using blockchain would allow patients to control how, when, and by whom their information is used. By requiring interoperability and using blockchain, the patient's medical information will be accessible, secure, portable, and readily available when granted access by the patient.

Significant and positive implications for research and society are possible with a large databank of participants. Research studies that meet the criteria to be granted access to the databank would have access to significant amounts of patient data that could bolster the power of their study to be generalizable to the public. Subpopulations of patients with identical variants or mutations could be identified and invited to participate

in clinical trials. Drugs developed using *Lifespan* as well as clinical trial results would be made available to the patients who participated at either no cost or significantly reduced prices compared to market value. The databank could also facilitate bone marrow and organ donor matching. Finally, granting controlled access to law enforcement agencies investigating serious crimes or missing persons may serve as a deterrent of crime.

Upon death, minimally invasive autopsies (MIAs) would be performed on those who died of known causes and weren't minors. Complete autopsies would still be performed on minors, suspicious deaths, or deaths where the cause was unknown. The autopsy report would include the decedent's cause and manner of death, pathology report, and final whole-genome sequence. The autopsy report would be the final information collected in order to complete and close a person's lifespan. By participating in *Lifespan*, a patient's funeral expenses would be covered. The creation of a necrogenomic registry would allow for individuals who didn't participate in *Lifespan* to have their information collected and stored in the system at the time of death.

The creation of *Lifespan* as a new paradigm in health care will require the creation of jobs that don't currently exist, the restructuring of health insurance and the health care delivery system, the education of clinicians in genetics, a radical increase in the workforce for genetic counselors and bioinformaticians, and a drastic increase in the number of seats available at medical and health professions schools in order to increase the number of pediatricians, primary care providers, medical geneticists, and forensic pathologists that will be needed.

Lifespan is a revolutionary socio-technical system that seeks to improve the overall health outcomes of individuals by encouraging proactive, preventative, and

holistic health care using patient information and medical technology. The successful implementation of *Lifespan* could drastically reduce health care costs annually but even more so influence long-term, national economic prosperity by increasing the lifespan of healthier people who live longer. This could ultimately lead to a more productive national workforce.

SOCIO-TECHNICAL ARTIFACTS OF LIFESPAN

The development of new socio-technical systems is constructed from the interactions of people, institutions, and artifacts. Understanding these interactions and identifying the artifacts that give rise to new socio-technical systems can elucidate underlying politics, values, and knowledge systems. The design and evolution of the *Lifespan* scenario will be traced from the socio-technical artifacts and interactions that led to its establishment.

Both artifacts and technologies aid in ordering our lives (Winner, 2010). Technical artifacts can be viewed and interpreted in different ways by different groups (Pinch & Bijker, 1987), and artifacts can have political qualities (Winner, 2010). How socio-technical systems are created or exist can provide insight into how power and authority are organized and structured while allowing us to conceptualize how human life and activities will be altered or reconstituted with the implementation of a new socio-technical system (Winner, 2010).

THE U.S. HEALTH CARE SYSTEM

The current health care system is “one of the most complex socio-technological systems in modern societies” (Miller, Ross, Bennett, & Hurlbut, 2016, p. 537). The Organization for Economic Co-operation and Development (OECD) provides

information regarding health care and health outcomes for 35 member countries and other partnering countries. The United States currently spends more on health per capita and in relation to gross domestic product (GDP) than any other OECD country (OECD, 2015). The United States spent 16.4% of its GDP on health and USD 8,713 for each of its residents (OECD, 2015). According to the OECD (2015), the level of health spending in the U.S. was almost 40% higher than the next biggest spender and two-and-a-half times the average level of spending for all OECD countries. Despite the significant spending on health, the United States has an infant mortality rate of 5 deaths per 1,000 live births as compared to the current OECD average of 3.8 deaths per 1,000 live births placing it at a tie for 31 out of 44 countries (OECD, 2015). Additionally, life expectancy within the U.S. has seen modest gains as compared to other OECD countries with the U.S. being at 78.8 years of age, but it is still below the OECD average of 80.5 years of age (OECD, 2015). The U.S. tied at 27 out of 44 countries for life expectancy at birth (OECD, 2015).

The exorbitant spending on health by the U.S. compared to its overall health outcomes produces understanding as to how a system like *Lifespan* could be welcomed and implemented. The current fee-for-service model within the U.S. health care delivery system has at times been referenced as ‘sick care.’ A new socio-technical system for health care would aim to lower costs, increase health outcomes, improve quality, and proactively influence (rather than reactively treat) the overall health of patients (Berwick, Nolan, & Whittington, 2008).

ARTIFACTS OF LIFE AND DEATH

Within the U.S., life and death are officially documented through birth and death certificates. Documentation for both life and mortality proved to be an administrative

strategy by the state or government to manage society by numbers through the collection of data and use of statistics (Porter, 2003). The standardization of birth certificates in the U.S. occurred in the 1930's with a revision in 1989 that offered greater accuracy, uniformity, and completeness (Brumberg, Dozer, & Golombek, 2012). Diagnosing metabolic diseases like phenylketonuria (PKU) was what led Robert Guthrie to develop a method during the 1960's for newborn screening by collecting blood from a heel prick and placing it on filter paper for analysis (Paul & Brosco, 2013). The cards containing dried blood spots of individual newborns are known as Guthrie cards and are typically stored over a period of time (Paul & Brosco, 2013). Guthrie cards have recently experienced intense legal scrutiny and in some cases mandatory destruction due to potential violations of genetic privacy (Brase, 2014).

Each state within the U.S. determines if cause and manner of death are certified by a medical examiner (possesses formal medical training), a county coroner (elected official that may or may not possess formal medical training), or a mixture of both (National Research Council, 2009). Davis (1997) traces the history of death certification and how it originated as a method to generate money through fines for the crown by classifying murder or suicide to the use of autopsy to generate information for public health and medical science benefits. Medicolegal autopsies are typically performed for unusual or suspicious deaths as well as the death of infants and adolescents to assess the presence of disease, the manner of death, and cause of death (National Research Council, 2009). Autopsies rates have declined significantly in the past decade and are not currently performed on a majority of decedents within the U.S. despite their potential to provide useful information about disease, health, and genetics (Burton & Collins, 2016).

GENOMIC ARTIFACTS

The completion of the Human Genome Project in 2003 laid the foundation for imagining, designing, and completing a massive “big science” project involving genomics. The Human Genome Project led to the creation of laws and the advent of precision medicine (Collins, Morgan, & Patrinos, 2003). Concerns about potential discrimination caused congress to enact the Genetic Information Nondiscrimination Act (2008) known as GINA which prohibited the use of genetic information for health insurance and employment decisions. Precision medicine was one of the top biomedical policies within the Obama administration as indicated by the launch of the million person Precision Medicine Initiative (PMI) – All of Us program which was budgeted \$200 million in FY 2016 (U.S. Department of Health and Human Services, 2016). The bipartisan 21st Century Cures Act (2016) was one of the final laws signed into effect by the Obama administration to provide \$1.5 billion over ten years to PMI. From 2012 to 2015, the National Institutes of Health has spent on average \$7.395 billion on genetics annually (National Institutes of Health, 2016). Significant advances in genomic sequencing over the past two decades have caused a shift in genetic testing of single genes to the testing of the whole-genome.

Genetic testing, national genomic registries, and biobanks are all biomedical technological systems that have important implications for those who interact with them. Biomolecular databases and biobanks are socio-technical systems that establish science communication regimes (Hilgartner, 1995) and should allow for continuous interaction and input from participants throughout their involvement (Saha & Hurlbut, 2011). Understanding the human genome requires large-scale citizen participation (Pillar,

Isakov, & Shomron, 2014) and should actively engage participants as agents who possess memory, knowledge, imagination, insight to help govern the system (Jasanoff, 2003). These technological systems are also impacted, shaped, and evolved by users, communities, and societies. For example, the technological architecture and deployment of breast cancer genetic testing differs greatly within the United Kingdom compared to the United States and subsequently yields varying user experiences depending on the particular system (Parthasarathy, 2005).

Well-established national registries like the Danish Civil Registration System, which houses information about all individuals alive and living in Denmark, have the potential to significantly increase knowledge and understanding about diseases and population health (Pedersen et. al., 2006). The potential for a Danish necrogenomic registry linked to the Danish Civil Registration System could supply genomic data from decedents to be matched with long-term health outcomes already tracked within their database (Hedley & Christiansen, 2016). The UK Biobank (2017) has collected blood, saliva, and urine samples from 500,000 people for future analysis while the leading genetics company in Iceland, deCODE, already has over one-third of the Iceland population's DNA in a database (Kirby, 2014). The 51,515 participants within the Estonian Biobank of the Estonian Genome Center (2017) signed broad informed consent when they donated their genes. Kuwait is the first country to ever pass a law that will require all citizens and visitors to provide a DNA sample to be stored in a governmental database (Lee, 2016). The Kuwaiti law is not meant to provide information to citizens about their health, to diagnose disease, or perform biomedical research (Lee, 2016). There have also been genetic test registries established by agencies like the NIH to help

alleviate clinician and patient confusion by centralizing critical information about available genetic tests and result interpretations (Kuehn, 2010).

Emerging technologies, research, and creative initiatives intertwine to establish a rapidly evolving socio-technical system involving genomics. Through a randomized clinical trial known as the BabySeq Project, researchers at Brigham and Women's Hospital and Boston Children's Hospital performed whole exome sequencing (WES) on newborns to determine potential childhood illnesses (Fliesler, 2016). The Deciphering Developmental Disorders Study (2017) recruited nearly 14,000 children with severe undiagnosed developmental disorders and sequenced the exomes of 4,293 families to find 94 genes enriched through *de novo* mutations. New technologies like liquid biopsies (Chen, 2016) and immunosignature systems (Stafford et. al., 2014) are attempting to perform early detection of cancer through the use of blood. Veritas offers whole-genome sequencing at \$999 which includes sequencing the patient's entire genome, a phone app to access their genome, and the ability to speak with a genetic counselor (Regalado, 2016). The era of the \$100 genome using whole-genome sequencing is near according to Illumina (Keshavan, 2017).

Human longevity and lifespan are of interest to many people including entrepreneurs, researchers, individuals, and the government. The human lifespan is presumed to be fixed with 122 years of age being the maximum age at death ever recorded for a person (Dong, Milholland, & Vijg, 2016). Human Longevity is a company that offers the Health Nucleus program in which individualized services including DNA sequencing, analysis of a person's microbiome and metabolome, and physical scans are offered to enrolled patients (Zimmer, 2015). Through the collection and analysis of

various fluids and tissues from the body, minimally invasive autopsies (MIAs) instead of full autopsies could increase the rate that autopsies are performed while providing additional information at death pertaining to not only disease but aging and longevity (Kean, 2015).

LIFESPAN – GOVERNANCE, ETHICS, AND VALUES

Patients, providers, healthcare institutions, and regulators will all need to be smart about how they design and inhabit the socio-technical relationships that link health information devices to values, behaviors, sensibilities, relationships, and institutional practices” (Miller, Ross, Bennett, & Hurlbut, 2016, p. 536).

Lifespan is an extremely complex socio-technical system that has the potential to treat, cure, and prevent disease and disability; however, technological optimism for the system should be approached with caution. For this emerging technology, responsible innovation through anticipatory governance should be enacted at the initial stages of concept through development and beyond. Anticipatory governance is defined as “a broad-based capacity extended through society that can act on a variety of inputs to manage emerging knowledge-based technologies while such management is still possible” (Guston, 2008, vi). Multiple stakeholders including agencies, experts, and citizens should participate in the anticipatory governance of *Lifespan*.

Regulatory agencies will need to consider the reproducibility, reliability, and accuracy of results, how information is conveyed to patients, and how new methods and information will be relayed back to participants. The security and privacy of each individual’s genomic, medical, social, behavioral, and environmental information will be of paramount importance. Governmental agencies like the NIH, HHS, CMS, and many

more will be responsible for a multitude of large-scale tasks including the long-term creation and implementation of the infrastructure for *Lifespan*, population health analysis and outcomes, defining reimbursement rules, and many more. The legislative and executive branches will need to work together collaboratively and in a bipartisan fashion to successfully create laws and funding mechanisms to implement and sustain the system. The judicial branch will become involved as the new paradigm for health care interacts with individuals from all walks of life.

Vulnerable and protected populations will require the utmost care and attention when forming the system. The participation and recommendations from marginalized communities who have been coerced and taken advantage of by research and researchers in the past should be welcomed and included. Incidents like the Tuskegee syphilis study, the forced sterilization of the mentally disabled as well as Native American women, and Henrietta Lacks are only a few examples of why it will be imperative to involve key stakeholders to ensure extreme vigilance and anticipatory governance will protect and serve their sovereignty, respect their past, and honor their future.

Legal issues within personalized medicine may abound with regulatory hurdles slowing progress juxtaposed to the potential acceleration of precision medicine due to physician and manufacturing liability (Marchant, Campos-Outcalt, Lindor, 2011; Marchant, 2007). Legal consequences for violating patient confidentiality currently exist but will need to become more robust for a system like *Lifespan*. In addition, foresight will allow for the creation of legislation and laws that will prevent discrimination not only for employment and health insurance but all forms of discrimination including but not limited to disease predisposition as well as disease presentation. The Affordable Care Act

(ACA) was a crucial bill for people with Huntington's disease since it closed a loophole that had permitted insurance companies to refuse coverage if a person had a known illness which might be discovered through genetic testing (Eriksen, 2017).

The allowance of law enforcement agencies and federal agencies like the Federal Bureau of Investigation (FBI) to have limited and controlled access to *Lifespan* could prove to be a double-edged sword. Extremely violent crimes may decrease by knowing that law enforcement agencies could access individual information including whole-genome sequences in addition to data supplied by wearables including but not limited to distance traveled, location at a given time, temperature, and heart rate. Counter to the positive of potentially decreasing crime, individuals may be extraordinarily apprehensive to donate their information into *Lifespan* should law enforcement or the government be able to use the information for broad surveillance, dragnets, or without strict limitations like requiring a warrant or subpoena for database access. Other potential legal implications include determining paternity at birth for eligibility to enter *Lifespan*. At first, this may appear controversial and unnecessary, but ultimately, this policy would aid in identifying fathers for single mothers, reduce paternity fraud, and reduce legal cases that may occur years later regarding custody, visitation, and child support should the presumed father not be the biological father. Another legal issue to consider is when should genetic predispositions (like *BRCA1/2*) or fatal genetic conditions like Huntington's disease be revealed to children, minors, or young adults. These are only a few of the numerous legal ramifications and laws that would need to be anticipated prior to the system's deployment.

Determining the types of consent and systems to be used for data-sharing will have significant consequences for all involved. A major debate regarding consent within biobanks revolves around whether broad or dynamic consent should be enacted (Steinsbekk, Myskja, & Solberg, 2013). The use of blockchain for dynamic consent may be feasible and allow individuals to select how and when their personal information is used and shared; however, broad consent is gaining traction due to the endorsement provided within the revised Common Rule (Menikoff, Kaneshiro, & Pritchard, 2017). Whether the system is publicly available via open-access, semi-open, or fully closed will determine how individual information is presented and used. There is a high probability that de-identified data within an open-access platform for data-sharing could be re-identified in the future as genomic technology accelerates. Semi-closed systems that enact a gatekeeper function use “a distinct entity to house information in a central repository, with access to specific data sets that are provided to qualified research teams on the basis of a research proposal review by an independent expert committee” (Bertagnolli, et. al., 2017, p. 1178). The type of consent and platform selected for *Lifespan* must instill safety, trust, and security for the individuals whose data is collected and stored within it.

Insurers and employers will play a vital role in the success or failure of a socio-technical system of this scale. Insurers and employers would require the benefits and cost of *Lifespan* to outweigh the benefits and costs of the current system. Should *Lifespan* produce a healthier workforce, the employers would benefit greatly by having employees who take less sick leave. Using a delayed aging scenario, Goldman et. al. (2013) illustrate how slowing the aging process (senescence) to increase life expectancy to 2.2 years could

ultimately yield \$7.1 trillion over a fifty year period of time. This is one of the economic arguments for insurers, employers, and those within the health care delivery system to adopt a system like *Lifespan*. For those who elect to not join the employee sponsored or governmental sponsored plan within *Lifespan*, the insurance companies would be able to charge a much higher rate compared to the reduced amounts for being enrolled in *Lifespan*. Inducement to participate by employers into a system like *Lifespan* is a possible slippery slope and should be approached carefully, but the goal would be for people to participate from birth which would seamlessly transfer whether employed or not. In addition, incentives through *Lifespan* could provide all forms of insurance versus insurance policies outside of *Lifespan* which would only provide health insurance at a higher cost. One study provides insight regarding how people react when they learn about possible increased susceptibility to a debilitating disease – Alzheimer’s. People who tested positive for Apolipoprotein E (APOE) had no significant changes in their purchasing of health, life, or disability insurance, but they were more likely to change long-term care insurance by 5.76 times due to an increased predisposition to develop Alzheimer’s (Zick et. al., 2005). Individuals do change their behaviors regarding purchasing insurance when confronted with a deadly or debilitating genetic disposition. *Lifespan* would provide peace of mind to individuals since they would be protected against all forms of discrimination while having access to all forms of insurance at an affordable price regardless of predisposition, disability, or disease.

Economic incentives have the potential to transfigure precision medicine through the use of pricing, access, innovation, and development (Stern, Alexander, & Chandra, 2017). Economics and incentives drive large-scale sociotechnical systems like *Lifespan*.

Patients who take the anticoagulant drug, warfarin, have tremendous variability for optimal dosing and efficacy. Should genetic testing be used to properly dose for warfarin, then substantial savings could be generated within the health care delivery system by preventing an estimated 17,000 strokes annually (McWilliam, Lutter, & Nardinelli, 2008, 2006). Another example is the estimated annual health care cost savings of \$6.04 million if patients who were diagnosed with metastatic colorectal cancer were screened for the KRAS gene before beginning treatment (Shankaran et. al., 2009). With these two examples alone, the cost savings are tremendous. Imagine the long-term savings for the health care delivery system, the unnecessary disabilities prevented, and the productive lives saved if these types of indicators and predispositions were readily available to individuals at birth.

Medical education will need to drastically change to include personalized medicine within the curriculum being taught to future clinicians. An entire new field of health professions may emerge to meet the growing demands that *Lifespan* would cause. A new type of health professional may ensure annual physicals are conducted, design the patient interface or dashboard to interact with their information, use bioinformatics to analyze and synthesize vast amounts of data on a constant basis, counsel patients about their genetic, social, and environmental information, engage in behavioral interventions and risk education, process insurance, remove people from insurance, and identify populations for clinical research due to their available information.

Society as a whole will need to determine if this technology's benefits are greater than its potential costs. This can be achieved by assessing and understanding society's public values which are defined as "providing normative consensus about (a) the rights,

benefits, and prerogatives to which citizens should (and should not) be entitled; (b) the obligations of citizens to society, the state, and one another; and (c) the principles on which governments and policies should be based” (Bozeman, 2007, p. 13). Health is a public value held in high esteem by many citizens within a society; however, other public values may take priority over health including but not limited to freedom, autonomy, privacy, safety, and justice. One way to assess a large-scale, public scientific system like *Lifespan* is through public value mapping which is an “approach to identifying the public value premises of public policy and then tracking their evolution and impacts on policies and, ultimately, social outcomes” (Bozeman & Sarewitz, 2011, p. 13; Bozeman, 2003).

Citizens are essential for the successful development and governance of any complex socio-technical system, and this holds true for *Lifespan*. Individuals are at the core of this system because no matter who the individual is – everyone eventually gets sick. Each individual is uniquely complex with their own identity, genetics, fingerprints, personality, behaviors, attitudes, and values. A system like *Lifespan* could contribute greatly to the knowledge system involving life and death, but it should not be viewed as a deterministic system that will find a cure for all diseases. Instead, the goal with a system like *Lifespan* is to 1) amass a substantially large amount of individual participants to accurately assess disease risk; 2) better understand how multiple genes, the environment, medical history, and social factors affect disease states; 3) find treatments for diseases if not cures; 4) reward and honor individuals who participate in the system; 5) provide better health outcomes by lowering cost, spreading risk, incentivizing participation, and improving quality; 6) increase the health and overall lifespan of those involved; 7) proactively rather than reactively address disease risks and predispositions; 8) provide a

personalized interface or dashboard for real-time assessment of an individual's current health, relevant clinical trials, and a centralized place for the storage of all health information including medical records, and 9) incrementally record individual human life from birth until death.

Understanding the values of individuals during the creation of a complex socio-technical system can significantly increase the system's probability of success. One way to assess individual attitudes about consent and data-sharing for biobanks is to directly ask individuals about their attitudes and values. Of the 13,000 individuals surveyed for one study, 66% indicated that they would participate in a biobank, and 88% indicated that they wanted to know the repercussions for misuse of their data (Sanderson et. al., 2017). In addition to assessing individual attitudes about participating in a biobank, an assessment of individual values and preferences should be undertaken prior to enrolling in a system like *Lifespan*. Previous studies have surveyed public opinions about participating in large genetic cohort studies as well as public preferences for returning results from genetic research (Bollinger et. al., 2014; Kaufman et. al., 2008). A Patient Value Index (PVI) could establish norms and expectations for each individual including re-contact regarding new discoveries, desire to know or avoid information, risk and uncertainty tolerance, willingness for disclosure of information to immediate family regarding heritable disease, potential for self-harm with disclosure of a terminal genetic condition, and if relaying information is acceptable even if a potential change in self-perception or identity could occur. A standardized Patient Value Index (PVI) could help clinicians as well as patients navigate the complexity of individual values and beliefs by

identifying in advance how they would like to interact with the system and the information it provides both currently and in the future.

CONCLUSION

Disease is a complex continuum that is rarely binary, and the constant yearning to simplify and understand complexity especially for diseases is part of human nature. A shift in individual understanding will need to occur for many complex disease states like obesity, diabetes, autism, and heart disease. Risk for developing a disease can be powerful for an individual even when uncertainty is present. For some individuals, knowing risk provides the ability to increase proactive planning and interventions by initiating continuous monitoring, modifying behavior and environment, joining disease advocate groups, and taking preventive measures including prophylactic surgery. For other individuals, knowing risk combined with uncertainty causes paralysis, anxiety, and disrupts daily life. Both individuals and their values should be able to co-exist and interact with a socio-technical system like *Lifespan*, and the design of the system will be strengthened by involving multiple stakeholders with differing values from its inception.

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