THE ETHICS OF GENETIC TESTING AND SCREENING IN THE U.S. MILITARY

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Abstract

Significant ethical issues arise in the context of military policies and genetics. Advancement in biotechnology has generated unfathomable insight into the role of the human genome on health. The U.S. Military routinely collects genetic information and conducts genetic testing but is not subject to some of the protections afforded civilians. The Genetic Information Nondiscrimination Act (GINA) of 2008 was a preemptive civil rights law that sought to prohibit genetic discrimination, but the U.S. Military is exempt from complying with GINA standards for employment nondiscrimination. I argue that it is unethical for servicemembers to undergo mandatory genetic testing and screening in the absence of robust protection of genetic information and against discrimination. In order to identify ethical issues that are significantly different in the military vs. the civilian context, I will here explore the role of current military practice, including TRICARE health insurance, the Disability Evaluation System, human subjects protections for military personnel, required genetic and health screens, and Department of Defense and branch-specific genetic information policies. Then, I will illuminate the ethical obligations of the military institution and the duty to protect the individual servicemember. In this paper, I draw on three unique cases that convey different ways in which military personnel are vulnerable to genetic discrimination. I will offer an ethical analysis of perceived benefits and harms of using genetic information in each of the three cases, drawing on the principles of autonomy, non-maleficence and justice. Specifically, I argue that: (1) due to the all-encompassing demands of the U.S. Military and the control it wields over the lives of
servicemembers, the military has an obligation to promote what little autonomy servicemembers have, (2) the principle of nonmaleficence is violated by the consequences of mandatory genetic screening, which primarily constitute career repercussions and emotional distress, and (3) mandated genetic screenings in the absence of rigorous genetic information protection policy is unjust because servicemembers comprise a vulnerable population. I conclude that the harms of exempting the U.S. Military from GINA outweigh the perceived benefits and suggest an opportunity to reframe genetic information protection and nondiscrimination into more rigorous and military-specific policy.

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Dedication

This work is dedicated to my family, for their undying support throughout this process. To my parents, Brent and Kristin, who inspired me to work with the servicemember population and teaching me resilience. To my sister, Abby, for reliably lending an ear to my thoughts at every moment. To my dog, Cooper, whose fuzzy face stuck by my side during the hours and hours of writing. And finally, to my grandparents, Tom & Grace and Ed & Jane, who gave me the opportunity to escape my bedroom during a pandemic and unwaveringly supported my studies.
List of Tables

Table 1. Vulnerability to Genetic Discrimination at Different Stages in U.S. Military Career.................................17
# Table of Contents

Abstract.................................................................................................................................................... ii

Acknowledgements..................................................................................................................................... iv

Dedication.................................................................................................................................................. v

List of Tables............................................................................................................................................. vi

1. Introduction.......................................................................................................................................... 1

   2.1. Background
   2.2. U.S. Military Exemption

3. Current Military Practice ..................................................................................................................... 5
   3.1. Medical Standards
   3.2. TRICARE Insurance
   3.3. Disability Evaluation System (DES)
   3.4. Human Subjects Protections of Military Personnel Undergoing Experimental Treatment
   3.5. Health and Genetic Testing & Screening Procedures and Policies
      3.5.1. G6PD
      3.5.2. SCT
   3.6. DoD and Branch Policy on Genetic Information


5. Military Duty to Protect........................................................................................................................ 18

6. Ethical Implications of Genetic Testing & Screening in the U.S. Military............................................ 19
   6.1. Autonomy
   6.2. Beneficence & Nonmaleficence
   6.3. Justice
      6.3.1. Distributive Justice
      6.3.2. Structural Justice
   6.4. Genetic Exceptionalism
   6.5. Omission vs. Commission

7. U.S. Military-specific Genetic Information Protection and Nondiscrimination Policy....................... 28
   7.1. The Sort of Genes We Screen for Matter
   7.2. The Relationship Between Policy and Scientific Validity
   7.3. Protecting Vulnerabilities
   7.4. Counseling & Education Proposals
   7.5. Protection of Familial Information
   7.6. DoD-level Policy
1. Introduction

The field of genetics has grown exponentially in the past half century, giving rise to incredible technologies and insight into our own genetic composition. The Human Genome Project completed its 13-year mission in April of 2003, producing a fully sequenced blueprint for human DNA and launching civilization into the genetic revolution. This advancement fostered the emergence of personalized medicine, in which diagnoses and treatments can be tailored to individual patients in order to maximize safety and efficacy. Buried ancestry information and insight into one’s genetic composition became widely accessible via direct-to-consumer genetic testing. These innovations did not come without consequences, as genetic discrimination and the emotional toll of seemingly deterministic information outpaced ethical conduct and policy development. Cultivating a scientific understanding and application of genetic knowledge posed an important ethical question regarding ownership and use of one’s genetic information. To protect against potential misuse of this information, the US Senate enacted a preemptive civil rights bill in 2008, called the Genetic Information Nondiscrimination Act (GINA). However, GINA fails to protect servicemembers (SM) in the U.S. Military. This exemption allows for the U.S. Military to require genetic screening and testing of several genes of interest for all SM, prospective and current. In lieu of prohibitive legislation, military personnel are subjected to mandatory genetic testing that can impact eligibility, occupational specialty, forced retirement, and disability benefits.
In this thesis, I argue that it is unethical for SM to undergo mandatory genetic testing and screening in the absence of robust protection of genetic information. First, I will describe current standards of practice within the U.S. Military, including TRICARE health insurance, the Disability Evaluation System (DES), human subjects protections for military personnel, required genetic and health screens, and Department of Defense (DoD) and branch specific policies regarding genetic information. Next, I will raise general ethics issues that arise in the military not specific to genetics. I will discuss the ethical obligations of the military, including the duty to protect, and demonstrate how military personnel comprise a vulnerable population by introducing three cases that expose different vulnerabilities corresponding to different timepoints along an SM’s career. Finally, I will offer an ethical analysis of benefits and harms of using genetic information in each of the three cases, drawing on the principles of autonomy, non-maleficence and justice. Specifically, I will argue that: (1) due to the all-encompassing demands of the U.S. Military and the control it wields over the lives of SM, the military has an obligation to promote what little autonomy SM have, (2) the principle of nonmaleficence is violated by the consequences of mandatory genetic screening, which primarily constitute career repercussions and emotional distress rather than medical benefits, and (3) mandated genetic screenings without detailed and rigorous genetic information protection policy is unjust because SM comprise a vulnerable population. Finally, I will conclude that the harms of exempting the U.S. Military from GINA outweigh the benefits and suggest an opportunity to
reframe genetic information protection and nondiscrimination into more rigorous and military-specific policy.


2.1. Background

In 2008, the United States passed the Genetic Information Nondiscrimination Act (GINA), protecting Americans from discrimination by health insurance and employers based on genetic make-up. Genetic information was defined by GINA as, “family medical history, manifest disease in family members, and information regarding individuals' and family members' genetic tests.” This act prohibits employers and health insurance companies from requiring genetic testing or making decisions based on genetic information alone. Many states have their own laws regarding genetic discrimination, some rigorous and some weak- GINA is designed to establish a standardized protection against genetic discrimination for all Americans to which all relevant entities must comply. There are two main components to GINA: the first outlines the restrictions preventing genetic discrimination by health insurance, and the second prohibits genetically discriminatory actions or decisions by employers.

Title I covers health insurers or health plan administrators, preventing them from requesting or requiring genetic information of an individual or an individual's family members, or using such information for decisions regarding coverage, rates, or preexisting conditions.
However, this does not apply to life, long-term, or disability insurance policies.

Additionally, GINA includes a, ‘research exception,’ that allows health insurers and group health plans engaged in research to request (but not require) that an individual undergo a genetic test.

Title II covers employment, prohibiting employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment. However, federal government employers such as the U.S Military are exempt from adhering to these protections.

Though there have been a few cases of genetic discrimination, GINA was not intended to serve as a response to instances of unethical misconduct. Rather, it was designed to prevent such occurrences of discrimination from happening at all.

2.2. Limitations

Title II of GINA covers the legal obligations of relevant entities to comply with the prohibition of genetic discrimination in considering offers of employment. This section contains an exemption that will be the focus of this thesis. It states that the employment protections offered by GINA do not extend to the U.S. Military or federal employees. This means that the military may make employment decisions based on genetic information. It is important to note that GINA takes the form of a negative right. Per GINA, American civilians are granted freedom from genetic discrimination, they are not granted access to special accommodations due to genetic differences. We can compare this to the American’s with Disabilities Act (1990) which
prohibits discrimination based on disability and guarantees accommodations to improve the public and private environment for people with disabilities. This is an important distinction that will inform the shape that future military policy ought to take, and will be discussed further in Sections 6.2 and 7.6.

3. Current Military Practice

In order to orient the reader to the ethical dilemma at hand, it is necessary to describe pertinent information about military procedures and policies that is distinct from those relevant to civilians.

3.1. Medical Standards

The U.S. Military enjoys allowances when it comes to genetic information that other employers do not have for many reasons having to do with the strength of the military institution and the need to protect service members. All U.S. military branches have utilized medical disqualifiers in the screening process for Americans interested in joining the service long before genetic disqualifiers came into existence. For example, if someone has diabetes mellitus, anemia, or even a peanut allergy, they may be subject to dismissal from the screening process and deemed ineligible for service. Medical standards are part of the determination of
fitness for duty and must be met annually throughout the career of an SM in order to continue component operations.

3.2. TRICARE Insurance

TRICARE Health Plan is the health insurance program for U.S. Military SM. All SM are eligible to participate in TRICARE insurance, in fact, all active-duty SM are required to be covered. TRICARE health insurance operates nearly identically to its private health insurance counterparts. Similar to private health insurance, TRICARE plans have annual premiums, deductibles, catastrophic caps, and out of pocket costs. For participating TRICARE members, TRICARE itself falls under the Title I protections of GINA concerning health insurance, preventing coverage consideration, underwriting, or premium setting on the basis of genetic information.

One of the main ethical concerns raised by the U.S. Military exemption from GINA is the inconsistency promising to protect TRICARE members within Title I and the ability for the military to determine who may acquire that membership through offers of employment, ultimately restricting access to TRICARE health insurance. Eligibility for TRICARE is contingent on an offer of employment from the armed forces or familial relationship to an SM. The lack of nondiscrimination protections afforded to the employment process for the U.S. Military can indirectly limit an individual from enrolling in a health insurance plan (TRICARE). Therefore, genetic information may affect one’s ability to access TRICARE health insurance.
3.3. Disability Evaluation System (DES)

The Disability Evaluation System (DES) determines the fitness for duty, separation, or retirement due to disability. This process may remove an SM from service, provide financial disability benefits, or determine a lack of causation between military service and disability. In the event that an SM is recommended for discharge, separation, or forced retirement, access to TRICARE halts and the DES collaborates with Veteran Affairs on continuity of health care. The VA Benefits Delivery at Discharge program exists to help ease this transition, offering legal and policy guidance in order to extract maximum benefits from the VA Health system. The Veteran Affairs Schedule for Rating Disabilities (VASRD) is used as a calculator of a sort to determine how severely the SM’s condition impedes their ability to work, care for themselves, and care for family. The VASRD is especially important in referring SM with congenital or developmental defects to the DES, as they must demonstrate that military service aggravated or superimposed disease. A SM’s disability or disease is not compensable if it is viewed as the result of a preexisting condition. This can be especially problematic with the presence of unknown genetic conditions manifesting during military service, complicating the causal agent responsible for symptoms. This will be expanded upon in Sections 3.6 and 4.

3.4. Human Subjects Protections of Military Personnel Undergoing Experimental Treatment

It is DoD policy that military personnel be provided the best possible medical prevention and treatments while operating under assignment, which includes countermeasures to
chemical, biological, or radiological warfare or terrorism and public health threats. In order to fulfill such an obligation, the DoD collaborates with the Food & Drug Administration (FDA) to provide SM with the best possible medical care through force health protection programs, military-specific Emergency Use Authorization (EUA) and Investigational New Drug (IND) applications. Procedures surrounding the option to refuse investigational treatments or obtain a waiver of informed consent are unique to the military and ought to be understood in the broader context of research ethics.

Military-specific EUA forms permit implementation of an unapproved medical countermeasure in response to a declaration of emergency issued by the Secretary of Health and Human Services. If the EUA that is granted provides recipients the option to refuse administration of the product, the President, upon request from the Secretary of Defense, may grant a waiver of an option to refuse to SM (E3.4, DoDI 6200.02, 2008). Such a waiver would eliminate SM choice with regard to whether they want to undergo the investigational treatment, effectively requiring military personnel to participate in research.

IND protocols are used in research involving a drug or medical device for novel use in preventing or treating illness and are subject to FDA regulations. The President, per request from the Secretary of Defense, may grant a waiver of informed consent to use an IND on SM within particular military operations. Circumventing the informed consent process is atypical in the context of human subjects research involving civilians. But in the military, a waiver of
informed consent is justified if the President determines that, “obtaining informed consent is not in the interest of national security,” (E4.2, DoDI 6200.02, 2008).

The involvement of military personnel in research has been of some interest in recent history, especially concerning the relationship between the hierarchical nature of the organization and the risk of undue inducement or coercion. The Code of Federal Regulations (CFR 45 part 46) Protection of Human Subjects describe special protections and criteria for vulnerable groups, recognizing the power dynamic at play within the military, and ensure additional safeguards that strive to protect the rights and welfare of study subjects. Additionally, the Final Report of the Advisory Committee on Human Radiation Experiments (1994) emphasized the importance of voluntariness in military personnel research and recommended that officers be excluded from recruitment in order to mitigate coercion and undue inducement.

The ethical obligations of the military to national security and to the individual SM will be discussed further in Section 5, but it here the point is to introduce the reader to current practices in the military regarding investigational treatments. In general, power dominates in the military, governing all decisions concerning SM and overriding their autonomy. The role of power will be discussed further in classifying military personnel as a vulnerable population in bioethics.
3.5. Health and Genetic Testing & Screening Procedures and Policies

Genetic screening is among the biotechnology advancements adopted by the military in order to improve the safety of SM. Other technologies, such as unmanned drones, have demonstrated the benefits of technology in war circumstances in reducing the risk of soldiers and airmen in the combat zone. Genetic screening is another response to adapting the exponentially growing field of biotechnology to the U.S. Military’s advantage. All U.S. Military branches currently require genetic screening for two gene variants (G6PD and SCT), both associated with increased risk in a particular combat zone. The test results affect the occupational specialty and may entitle the SM to health support or educational programming to mitigate the risk assumed by the presence of the gene variant. Additional educational programming, training support, and occupational accommodations are made for individuals who screen positive for either of these genetic tests.

3.5.1. G6PD: Glucose 6-phosphate dehydrogenase (G6PD) deficiency is associated with the decreased ability to metabolize certain drugs, particularly anti-malarial pharmaceuticals. All personnel entering or on active duty in the Military Services are screened for the presence of G6PD deficiency and results are documented in their electronic health record in accordance with DoDI 6040.45. Someone with a G6PD deficiency may be particularly at risk in malaria-prevalent combat zones, guiding tour deployments and international assignments.
3.5.2. *SCT*: The second screen is for sickle cell trait (SCT), which can manifest as sickle cell disease if both recessive alleles are present. While a history of sickle cell disease can disqualify a candidate from the recruitment process, presence of SCT is not a disqualifying condition. An SCT *carrier* will have one recessive allele and one dominant allele, and is at decreased risk for malarial infection. Conflicting evidence over the years has weakened any link between SCT and increased risk for mortality, but is still currently part of the screening process. Sickle cell trait screening will be done only on SM who meet demographic, clinical, or operational criteria. The results of testing must be documented in the SM’s Electronic Health Record.

In contrast with genetic screening, the US Army requires their SM to undergo HIV screening every two years as a part of preventative medicine. In the instance of a positive HIV result, SM are supported by trained HIV counselors. HIV is not a disqualifying condition, but it does have significant implications for SM assignments and military occupational specialty (MOS). For example, the HIV positive SM may be restricted from artillery or infantry positions and may not be deployed to a combat zone. Such measures are justified on public health grounds: to mitigate the spread of disease and to protect other soldiers in the event of a blood-exposure as a result of trauma or via a one-to-one emergency blood transfusion in the combat zone. Due to the distinct public health rationale for HIV screening, it is not different from genetic screening for G6PD-deficiency and SCT. Mandatory HIV screening is justified as a necessary violation of autonomy to protect the autonomy of those surrounding you. The same
cannot be said for G6PD and SCT screening. Therefore, the ethical issues raised by mandatory genetic screening are distinct from other mandatory medical screening in the armed forces.

3.6. DoD and Branch Policy on Genetic Information

The DoD does not have any policies that protect genetic information or prevent genetic discrimination. The Office of the Secretary of Defense, however, issued a memorandum warning against SM use of direct-to-consumer (DTC) genetic testing (2019). In this advisory, military personnel were warned against DTC selling tactics, offering incentives like military discounts. The office accuses DTC genetic tests of being largely unregulated and asserts that exposure of sensitive genetic information can adversely affect personal and operational risks, in part due to the obligation to disclose medical information that threatens fitness for duty. The memo raises important ethical issues with DTC genetic testing, but fails to elaborate on the role of genetic information in military operations.

Genetics is rarely mentioned in DoD Instructions and Directives. Currently, it appears that the main role genetics plays in DoD operations is contributing to the Disability Evaluation System. Within the evidentiary standards for determining compensability of unfitting conditions, the presumption of sound condition for active-duty members includes:

*Any hereditary or genetic disease will be evaluated to determine whether clear and unmistakable evidence demonstrates the disability existed before the Service member’s entrance on active duty and was not aggravated by their current period of military service. However, even if the disability is determined to have been incurred prior to entry on their current period of active duty, any aggravation of that disease, incurred during the Service*
members current period of active duty, beyond that determined to be due to natural progression will be determined to be service-aggravated. (DoDI 1332.18, 2018)

The idea of implicating genetic conditions as causes of symptoms and disability is not elaborated on within DoD instructions, but will be further discussed in Section 4 as an important source of vulnerability.

Although the DoD has not instituted any broad genetic nondiscrimination policies to protect SM, the U.S. Air Force does make explicit reference to genetic nondiscrimination in their equal opportunity policies. As a response to data revealing structural discrimination and injustice within the Air Force, the branch updated its Employment Opportunities Program to prohibit a broader range of discriminations that could arise among its personnel:

*Air Force Equal Opportunity (EO) Program (1.1.1)*

> It is against Air Force policy for any Airman, military or civilian, to unlawfully discriminate against, harass, intimidate or threaten another Airman on the basis of race, color, religion, sex, national origin, age, disability, reprisal, or genetic information... Unlawful harassment also includes creating an intimidating, hostile working environment. The use of disparaging terms with respect to a person’s race, color, religion, sex, national origin, age, disability, or genetic information contributes to a hostile work environment and must not be tolerated. Commanders and supervisors should ensure all types of harassment are corrected as soon as possible once they are made aware.

This airmen nondiscrimination policy explicitly prohibits interpersonal discrimination on the grounds of genetic information. This will be discussed further in Sections 6.3.2 and 7.6.

In short, the current U.S. Military practices involving medical fitness, disability, and genetic screening demonstrate that genetic information plays a significant role in the health
and wellness status of the SM, and does so in the absence of genetic information protection
and nondiscrimination policies. The absence of such protections is of particular concern from an
ethical perspective since SM are a vulnerable population.


The concept of vulnerability in bioethics refers to an unusually high susceptibility to
harm due to some sort of group membership or shared characteristic. Traditionally, an
increased risk of harm can result from (1) exceptionally hazardous situations and/or (2)
decreased capacity to safeguard one’s own interests, controls, or capabilities (Rogers, 2013).
Since SM fulfill both criteria, they qualify as a vulnerable population. The nature of the
occupation exposes SM to unusually dangerous situations. Whether it is in handling weapons or
operating in a combat zone, danger is part of the job. Moreover, the hierarchical organization
of the U.S. Military is characterized by an unavoidable power imbalance that can have
discriminatory and exploitative consequences.

The literature identifies several different types of vulnerability (Kipnis, 2003), two of
which are particularly applicable to the SM population. The first vulnerability is juridic: does the
subject answer to an authority who may have an independent interest in that participation?
The relationship between a military officer and enlisted member is a stark example of formal
and structural subordination. The same can be said of any SM of inferior ranking to another—
they assume a role of subordination to authority. This can both fuel instances of harassment or
discrimination and silence complaints or accusations of such behaviors. The second type of vulnerability is deferential: does the subject exhibit deferential behavior that masks an underlying unwillingness to participate? Similar to the juridic vulnerability, deference to authority can result in exploitation and discrimination that is not met with resistance. Juridic and deferential vulnerabilities primarily deal with power and will often occur simultaneously. We cannot remove the power imbalance from the organization of the U.S. Military, but illuminating points of vulnerability within the hierarchy can inform effective antidiscrimination policies.

SM experience distinct vulnerabilities at different stages in their military careers. The following cases depict three vulnerable stages:

**Case 1**

*A healthy, 18-year-old young man graduates from high school against the odds of low graduation rates and poverty that plague his county. He doesn’t have many career options in his community and, after talking to a recruiter, is eager to enlist in the military. He passes the physical examination with flying colors. Unfortunately, genetic screening performed on this prospective servicemember revealed several red flags and he is deemed ineligible for enlistment and his future is thrashed.*
Case 2

A successful, mid-career Naval pilot undergoes her annual physical to ensure her fitness for duty. A new gene variant was investigated and data suggested an association with impaired respiratory performance at high-altitudes. It is of particular interest to the military, so it becomes part of the genetic screening process for servicemembers. The test reveals that the pilot has the gene variant, and out of concern for her safety despite no evidence in her work performance, she is reassigned to a different occupation and forced to retire from flying.

Case 3

A recently medically-discharged servicemember suffering from kidney problems seeks disability benefits from the military. Their condition developed over the course of years of service, and they trust the military to assist in paying for treatment and care as they no longer have the military-issued TRICARE health insurance. Upon petitioning the military for disability benefits, the DoD physician screens for genetic abnormalities and finds a gene variant with evidence suggesting a high-risk for kidney disease. The military denies disability benefits to the veteran on the grounds that they were predisposed to the kidney condition and cannot prove that service was causally responsible.
As shown in Table 1, these cases expose different vulnerabilities that are dependent upon the stage of military career, and that are exacerbated by the absence of robust genetic information protection and nondiscrimination policies.

Table 1. Vulnerability to Genetic Discrimination at Different Stages in U.S. Military Career

<table>
<thead>
<tr>
<th>Cases</th>
<th>Timepoint Relative to Military Service</th>
<th>Vulnerability to Genetic Discrimination</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 1</td>
<td>Pre-military</td>
<td>Eligibility</td>
</tr>
<tr>
<td>Case 2</td>
<td>Active-Duty or Reservist Member</td>
<td>Occupational Specialty, Reassignment, Discharge</td>
</tr>
<tr>
<td>Case 3</td>
<td>Post-military</td>
<td>Continuity of TRICARE/health care Disability Benefits</td>
</tr>
</tbody>
</table>

In the case of prospective servicemembers, the main threat that genetic screening poses is to their eligibility for duty. For active and reservist members, the consequences of genetic screening can affect their occupational specialty or result in separation or medical discharge. For forced retirement or discharged servicemembers, genetic screening can interfere with continuity of health care and prevent the collection of disability benefits. These specific vulnerabilities ought to be addressed in a military genetic information protection policy, along with vulnerabilities that affect all servicemembers at any stage in their career, such as family utilization of genomic medicine (discussed further in Section 7.3-5). Before offering an analysis of the particular ethical issues raised by genetic screening in the U.S. Military, I will discuss the general ethical obligations the military has to its SM.
5. Military Duty to Protect

The primary function of a military is to engage in combat and to protect, broadly, its nation, which can include the nation’s interests, resources, and civilian population. Indeed, DoD Instructions permitting waivers of informed consent (section 3.4) forsake the autonomy of SM in the interest of national security. At first, it seems intuitive that military institutions should strive to protect the lives of SM, as they are also citizens that ought to be protected. However, it may not be self-evident what sort of obligations the military has toward its SM. One version of a duty to protect argument considers the conclusion, ‘the military is obligated to protect the lives of SM.’ The line of argument leading to that conclusion might look something like this:

\[
P1. \text{ A strong military inflicts damaging attacks and minimizes damage from opponent attacks.}
\]
\[
P2. \text{ A military has an interest in being strong.}
\]

\[\text{C. The military is obligated to recruit strong (i.e., healthy) SM (and) do what it can to keep them strong and healthy.}\]

This argument focuses on the interests of the military as an institution, asserting that a military has an interest in preserving the lives of SM because it is interested in absorbing minimal damage and being strong. Unfortunately, this argument does not quite illuminate the ethical obligations the Military has to SM in virtue of them being human, or speaking more plainly, the military fulfilling duties that are owed. To reach this conclusion, we can restate the
argument as, ‘The military has an obligation to protect the life that a SM leads.’ The line of argument leading to that conclusion might look something like this:

\[ P1. \text{ The SM undertakes a high burden by joining the military.} \]
\[ P2. \text{ The SM is interested in the life they lead.} \]
\[ P3. \text{ The military is extremely demanding in terms of risk and control.} \]
\[ P4. \text{ The SM is owed special entitlements from the military in return for service.} \]

\[ C. \text{ The military has an obligation to protect the life that a SM leads.} \]

Unlike the first argument, the second argument treats SM as ends in themselves and centralizes SM interests over military interests in determining ethical obligations. If we accept the second argument as valid, we can deliberate and make certain claims on the permissibility of mandatory genetic screening in the military.

6. Ethical Implications of Genetic Testing & Screening in the U.S. Military

There are several ethical arguments against mandatory genetic testing and screening in the U.S. Military in the absence of adequate protections. The first set of arguments concerns violations of key ethical principles including autonomy, nonmaleficence, and justice. Additional considerations include false beliefs about the power of genetic information and the intent of exemption.
6.1. Autonomy

One of the core pillars of bioethics, respect for autonomy is defined as freedom from control or constraint, full disclosure of information, and free choice or voluntariness. (Beauchamp & Childress, 2001) Respecting autonomy involves treating individuals as ends in and of themselves both providing and honoring choice. The genetic revolution presents to the military an opportunity to mitigate the risk of lives of service members in the combat zone by gaining insight into personalized health status and predisposition to conditions and diseases. As demonstrated in the arguments in Section 5, a strong military will not only have interests in strengthening its components, but also prioritize considerations that protect the interests of the SM. Preserving autonomy and promoting respect for persons is a form of protection. Soldiers sacrifice their lifestyle and risk serious injury or death by participating in the military. Such sacrifices entitle them to robust forms of protection from the military institution whenever possible.

The use of genetic information exacerbates the limits on choice that military SM experience. This sense of autonomy is more circumscribed within a military structure than is typical of autonomy for civilians. Genetic screening is one of the choices SM ought to have. Access to genetic information and health information can provide SM with a fuller and more detailed account of their physical capabilities in an operational military role. This can enhance the SM’s ability to give informed consent, whether that is when a prospective SM is considering enlistment or an Active-Duty SM is considering moving to Reservist status. No matter the
decision, genetic screening has the ability to provide more information that can be used or ignored at the discretion of the SM.

However, the imposition of mandatory genetic screening in the absence of genetic information protection and genetic nondiscrimination policy is problematic and violates autonomy. Respecting privacy, confidentiality, and choice preserves the autonomy of an individual. There is intense encroachment on privacy, confidentiality, and choice in the military, so military institutions ought to rigorously preserve what little privacy, confidentiality, and choice that remains. As a consequence of being exempt from having to operate in accordance with GINA, the military is permitted to require genetic screening and does not have to adhere to any protection of genetic information outlined by GINA. I contend that mandatory genetic screening is an unnecessary invasion of privacy, breach of confidentiality, and restriction of choice and, therefore, violates the autonomy of SM.

The military should not be permitted to mandate genetic testing or screening on prospective or current active or reserve component service members without robust genetic information protection policies in place to guard against genetic discrimination. The implications of mandatory genetic screening for autonomy are not unique to military personnel. Genetic testing places immense weight on reproductive freedoms and family planning decisions and involves potentially critical health information about biological family members who did not choose to join the military nor provide consent to learning of their own potential for genetic variations via mandatory military genetic testing. Despite the given
consent of an individual to undergo a genetic test in order to be eligible for military employment, the family has not consented to having that information revealed, breaching their autonomy. Genetic tests can provide enormous insight into a person’s health risks but are not necessarily a diagnostic tool. Mutations or markers detected in a genetic test may be used to diagnose a health condition, but far more often merely report on the probability of developing a condition or disease at some point in their lives.

Probabilities should not be used to determine eligibility for employment or service. Being deemed ineligible because one might develop a disease in the future would violate the autonomy of healthy people, eager to volunteer their service for an already life-risking occupation. Enlisting or becoming an officer in the military is an incredible choice to make, regardless of motivation. People volunteer to join the military for a variety of reasons including job security, patriotism, family traditions, scholarship, and access to resources such as education or health care. Removing that choice by introducing genetic disqualifiers that may not be relevant to the individual’s current health status violates respect for persons.

6.2. Beneficence & Nonmaleficence

Nonmaleficence and beneficence are also relevant to the ethical analysis of mandatory genetic screening in the military. Initially introduced by Beauchamp & Childress (1985), nonmaleficence encapsulates the doctrine to, ‘do no harm,’ and beneficence captures optimization of benefits. Nonmaleficence strictly refers to mitigating unnecessary harms and
beneficence refers to promoting benefits whenever possible. These two principles are intimately related, but offer distinct additions to this ethical analysis and demand different calls to action in policy.

The power of genetic testing and screening to identify clinically actionable health conditions has the potential to save the lives of SM by enhancing safety and preparedness on an individual basis. The information gleaned from this technology can be used to avoid unnecessary injury or fatality. Unfortunately, the pairing of mandatory genetic screening with a lack of genetic nondiscrimination protection not only fails to promote nonmaleficence and beneficence, but violate the principles for several reasons.

Genetic testing or screening is complicated. Requiring a person to undergo a genetic test poses risks not only to that individual’s emotional state, but that of their biological family as well. Undue emotional distress can be imposed on a SM and their biological family, violating the principle of nonmaleficence. Genetic testing can restrict perfectly eligible candidates from an employment opportunity and benefits (such as health care access) or cause unnecessary emotional distress.

Genetic testing or screening may exclude individuals who would otherwise strengthen the military, or at the very least eliminating them from participating in the sense of purpose or belonging that the military can provide, which violates the principle of beneficence for both the individual and the institution.
As mentioned above, the principle of nonmaleficence is related to but not interchangeable with beneficence. Nonmaleficence has to do with negative rights, whereas beneficence corresponds to positive rights. GINA is a type of negative right (section 2.2). GINA prohibits genetic discrimination, but does not entitle people with genetics-based sensitivities to accommodations that could improve their work environment, which is especially powerful when compared to the success of American’s with Disabilities (1995). This is particularly important in the context of using genetic information in the military: ought we impose negative rights prohibiting discrimination and misuse of genetic information, or ought we enable access to health resources and accommodations? I will explore this question further in Section 8.

6.3. Justice

6.3.1. Distributive Justice

Genetic screening that is currently mandated in the Military place additional burden on already marginalized demographics in the US. Gene variants indicating a G6PD-deficiency are most commonly found in people of African, Mediterranean, and Middle Eastern ancestry. SCT is most common in people of African ancestry, it is estimated that about 1 in 13 Black or African-American babies are born with this trait (CDC, 2020). This dramatically shifts any burden of genetic screening onto these populations. This can be alleviated by emphasizing benefit to the individual, connecting extra information about a person’s health status with extra protection and support. The consequences of emotional distress and occupational specialty repercussions
must be minimized in order for the benefit of these genetic screenings to outweigh the burden. In order to maximize individual benefit to this sort of information, the only genes that would be permissible for screening would be ones with well-researched penetrable gene variants, that are clinically actionable, and are situationally relevant (DeCastro, 2016). When these conditions are not met, genetic screening is unnecessary and burdensome, unfairly distributing harms amongst SM.

6.3.2. Structural Justice

Apart from a hierarchical organization in which power imbalance is inevitable, the U.S. Military must reckon with structural injustice by enforcing rigorous nondiscrimination measures. The military must acknowledge the social determinants and external pressures that influence disadvantaged groups to find the military an attractive or the only option at their disposal, resulting in an uneven distribution of demographics represented in the service member population. In discussing the permissibility of genetic screening in the U.S. Military, it matters what sort of genes and gene variants are being screened for, because it raises significant justice concerns.

The use of any genetic disqualifiers in military eligibility can be a slippery slope, paving the road to an unjustly homogenous military population. The list of disqualifiers is likely to grow as new tests or screens are discovered and made readily available for military use, risking the introduction of bias into the sort of gene variants that result in someone being deemed unfit for
duty. Such biased tests have the potential to exacerbate the health disparities, influenced by social determinants of health, experienced by minority and marginalized populations, such as people of color, women, and the LGBTQ+ community. Without protection from GINA, genetic disqualifiers can be implemented into the algorithm used for military eligibility, exacerbating discrimination and violating the ethical principle of justice.

6.4. Genetic Exceptionalism

If medical disqualifiers are ethically acceptable in determining military eligibility, then why do genetic disqualifiers pose an ethical dilemma? There are two main reasons why we ought to treat genetic information differently than other medical information given the complicated context of genetics in current society.

Firstly, the social narrative surrounding genetic and genomic information is overwhelmingly deterministic. The use of metaphors to describe the human genome such as, “blue print,” or “book of life,” has been well studied, and ultimately convey genes as concrete and unchangeable aspects that make up the core of who we are. However, the field of epigenetics defies such permanence by asserting that genes themselves undergo a tremendous amount of regulation and expression that can be heavily influenced by our behaviors, diets, levels of exercise, and even sleep patterns. So, although genes and their variants are not all inherently deterministic, society perceives them as such so we ought to approach genetic sequencing, testing, and screening carefully and uniquely from other medicine. This is especially
important when people confuse diagnostic with predictive genetic testing, which offers only a probability or risk that someone may one day develop a medical condition or be vulnerable to diseases.

Secondly, a distinct characteristic of genetic medicine is its innate quality of heritability: gene sequencing yields results that impact the entire biological family. This complicates how we normally approach consent in medicine and research, as any genetic sequencing, testing, or screening may yield information that subjects more than a single individual to certain clinical benefits or emotional and financial burdens. This can have implications for responsibilities toward people that are not the patients of a provider and permissibility of breaching confidentiality. Such a case may arise when a health care professional finds a significant variant in the results of a genetic test and ponders the right of at-risk family members to such information and the role of the health care provider in divulging that information. For these reasons, we are required to treat genetic information with special protections distinct from other medical information.

6.5. Omission vs. Commission

As previously discussed, the U.S. Military is explicitly exempt from Title II of GINA. The decision not to extend protection from genetic discrimination to servicemembers is an act of commission and therefore more egregious from an ethical standpoint than if it were an act of omission. Some philosophers have argued that the distinction between omission and
commission is morally irrelevant, primarily consequentialists who judge the value of a decision based on the consequences that follow. However, the motivations behind omission and commission are often dissimilar, so we may be resistant to the consequentialist conception of omission vs. commission (Spranca et al. 1991). It seems like motivations ought to matter, the difference being that omissions are typically brought about in ignorance compared to nefarious intentions associated with commission. For example, if Title II of GINA failed to mention the standing of the U.S. military or federal employees in its document, allowing legal teams to discover a loophole in the wording of GINA that allows for genetic discrimination in the military, lack of protection would be the result of omission. Nevertheless, the authors of Title II of GINA acknowledged the role of policy protecting SM against genetic discrimination in US military employment and explicitly exempts the institution from complying with such standards.

7. Important Considerations in Designing a U.S. Military-specific Genetic Information Protection and Nondiscrimination Policy

The limitations that emerged from GINA in the wake of passing into law can inform future genetic information protection and nondiscrimination policies. Here, I propose six important considerations that are critical to the process of developing a military-specific genetic information protection and nondiscrimination policy. Weaving these aspects into such a policy has the potential to enjoy the benefits of genetic testing and screening and protect autonomy,
promote nonmaleficence, and preserve justice in ways that a lack of a protective policy fails to accomplish.

7.1. The Sort of Genes We Screen for Matter

The sort of genetic variant that is required for screening in the absence of genetic information protection and nondiscrimination policy matters from the perspective of justice. Without fair protections, the burden of genetic screening repercussions will outweigh the benefits of involuntarily uncovered health knowledge. So, the burdens of genetic screening ought to be evenly distributed. As we’ve seen, mandating a genetic screen for a variant that is predominantly found in people of African heritage shifts the consequences of testing toward the African American population. In order to mitigate the burdens of genetic screening and distribute the benefits evenly across SM, the gene variants selected for screening ought to be penetrant, clinically actionable, and situationally relevant (DeCastro, 2016). These characteristics optimize the benefits, and therefore promote beneficence, gained from genetic screening and increase the probability that genetic screening for that particular gene variant would outweigh the harms. A successful selection of gene variants submitted for regular genetic screening in the armed forces would promote the principles of justice and beneficence.
7.2. The Relationship Between Policy and Scientific Validity

Anti-discrimination and health care access policy can help inform the threshold of validity for medical screens and tests. Screens and tests used to determine the presence of or risk for a certain medical condition are scientifically valid if they meet criteria for sensitivity and specificity. Sensitivity is defined as the ability of a test to correctly identify individuals who have a disease. A test with high sensitivity will minimize false negatives. Specificity is defined as the ability of a test to correctly identify individuals who do not have a disease, thereby minimizing false positives. The thresholds for specificity and sensitivity can be manipulated depending upon the clinical benefits and harms of letting an afflicted patient go untreated versus treating a healthy person for a condition they don’t have. The policy surrounding a medical condition can help direct the levels of specificity and sensitivity for proposed screens and tests. For example, a weak genetic nondiscrimination policy or lack thereof would have more harmful repercussions for positive genetic test results, therefore we ought to increase specificity to minimize false positives. If a there is a robust genetic nondiscrimination policy in place, patients can focus on the therapeutic benefits if a genetic variant is flagged, making increased sensitivity a higher priority in order to minimize false negatives.

7.3. Protecting Vulnerabilities

Table 1 features vulnerabilities unique to military components throughout different stages of a military career. Without a shadow of a doubt, military-specific vulnerabilities to
genetic discrimination ought to be confronted in a military-specific genetic nondiscrimination policy. That being said, the list of vulnerabilities when it comes to genetic information are not exclusive to the information presented in the table. There are significant features to genetic information and genetic nondiscrimination that ought to be implemented in a rigorous protection policy that are not unique to military components, but do grant the same genetic protections enjoyed by civilians.

7.4. Counseling & Education Proposals

The Military offers a number of educational programs following a positive result in either the G6PD or SCT genetic screening. I commend this directive, but recommend that counseling accompany any educational proposals. Due to the perceived deterministic nature of genetic information, effect on biological family, and reproduction & family planning, it is ethically appropriate that disclosure of a positive genetic test result be conducted in the presence of or by a genetic counselor. Disclosure of positive results in HIV screenings include counseling sessions, so there is an analogous obligation for the military to offer counseling in the context of positive genetic screening.

7.5. Protection of Familial Information

Military personnel are required to disclose medical information that has the potential to threaten readiness in the field. As such, a lack of genetic information protection and
nondiscrimination policy could dissuade biological family members of the SM from utilizing genetic services and personalized medicine. The field of genetics and personalized medicine hold great potential for better diagnosis and treatment of medical conditions, and it seems impermissible for the lack of a genetic information and nondiscrimination protection policy to inhibit non-SM from accessing such services. Therefore, an all-encompassing military-specific genetic information and nondiscrimination protection policy should offer an account of how familial genetic information and genomic medicine utilization ought not threaten nor be threatened by the status of the SM.

7.6. DoD-level Policy

Of the many things GINA accomplished, one of them was standardizing the minimal protections offered to civilians at a federal level. Many states have their own form of genetic protection policy, some weak and some robust. GINA offers a bare minimum level of compliance for all relevant entities. I believe something can be learned by this in developing genetic protection policies for servicemembers. Each branch may have their own statements or standards for genetic information protection, but a policy adopted by the Department of Defense that applies to all branches would standardize genetic nondiscrimination. The Army, Navy, Air Force, Marine Corp, and Coast Guard all have their own unique cultures and overarching responsibilities within the military. However, specific occupations span all branches. For example, if the Air Force were to develop robust genetic nondiscrimination
against gene variants that affect pilots, such as those influencing performance at high-altitudes, pilots in other branches would not share in those protections. Therefore, it would be most effective for the Department of Defense to develop, adopt, and implement a rigorous genetic nondiscrimination protection policy in order to hold all branches accountable. Through collaboration between the branches and active discussion surrounding the vulnerabilities presented by servicemembers, a more specific and effective genetic nondiscrimination policy can and should be established.

8. Conclusion

Genetic information can yield insight that may be of importance to individual SM and their families. Policy that supports the provision of genetic testing on penetrant, clinically actionable, and relevant variants can promote autonomy and mitigate harms (nonmaleficence). If the military determines that genetic testing should be mandatory because the benefits outweigh the risks, adequate protections must be in place. The U.S. military currently has the authority to make employment decisions on the grounds of genetic information through an explicit exemption from GINA without any guidelines surrounding the ethical use of genetic information. GINA did not offer suggestions nor guidance as to the implementation of such a policy that would be specific to the military branches. Considering the current practices, genetic screening, and medical information policies that reference genetics, there are particular vulnerabilities significant to the military that raise significant ethical concerns surrounding
mandatory genetic screening. In this respect, it was inappropriate for the US military to be exempt from GINA. However, this does provide an opportunity to reframe genetic information protections and nondiscrimination in the U.S. Military by using lessons learned from the effectiveness of GINA.

Genetic information is medical information with a deterministic narrative and familial implications that ought to be treated with special protections when considering breaches of confidentiality, invasion of privacy, and impact on choice. The US military is not held accountable to the protections covered in GINA afforded to civilians, which creates potential for abuse of that information and instances of genetic discrimination in an already vulnerable population. The control the US military has over the lifestyle of servicemembers raises the institution to a higher ethical obligation toward their servicemembers than a government may owe to their citizens. In order to promote the ethical pillars of autonomy, nonmaleficence, and justice, the US military ought to develop and adopt a robust genetic information protection policy that is tailored to servicemembers that can be used to determine ethical use or access to genetic testing and screening.
10. References


www.govtrack.us. 2007. May 6, 2021

https://www.govtrack.us/congress/bills/110/hr493


Kaiser, Jocelyn. "Genetic modification could protect soldiers from chemical weapons." Science / AAAS. -01-22T14:00:00-05:00 2020. Web. Jan 9, 2021


Kipnis, K. Seven Vulnerabilities in the Pediatric Research Subject. Theoretical Medicine 2003; 24: 107-120.


10.1093/oxfordhb/9780190245191.001.0001


<http://blogs.kentlaw.iit.edu/islat/2015/03/16/the-thin-red-line/>.
