



Ethical Issues in the Use of Direct-to-Consumer Genetic Testing by the Military

November 5, 2020



Overview/Agenda

- Membership
- Review Tasking
- Way Ahead



Membership



Chaplain Col (Ret.) Robert Certain
M. Div., D. Min.



David Resnik
Ph.D., J.D.
Chair



Mary Anne Dumas
Ph.D., RN, FNP



Matthew Wynia
MD, MPH



Overview of Tasking

On October 19, 2020, the Assistant Secretary of Defense for Health Affairs, directed the Defense Health Board (“the Board”) to

- Review current accuracy, privacy and security of DTC Genetic Testing companies
- Recommend guidance to Service member and health care professionals on DTC Genetic best practices
- Recommend guidance to the Department on the ethical use of prediction of suitability for initial and continued military service using DTC or clinical laboratory grade genetic testing



Background (1/4)





Background (2/4)



OFFICE OF THE SECRETARY OF DEFENSE
1000 DEFENSE PENTAGON
WASHINGTON, D.C. 20301-1000

DEC 20 2019

MEMORANDUM FOR: SEE DISTRIBUTION

SUBJECT: Direct-to-Consumer Genetic Testing Advisory for Military Members

It has come to the attention of the DoD that some direct-to-consumer (DTC) genetic testing companies are encouraging DoD personnel to purchase genetic ancestry and health information through the offering of military discounts or other incentives. These DTC genetic tests are largely unregulated and could expose personal and genetic information, and potentially create unintended security consequences and increased risk to the joint force and mission.

Exposing sensitive genetic information to outside parties poses personal and operational risks to Service members. DTC genetic tests that provide health information have varying levels of validity, and many are not reviewed by the Food and Drug Administration before they are offered, meaning they may be sold without independent analysis to verify the claims of the seller. Possible inaccuracies pose more risk to DoD military personnel than the public due to Service member requirements to disclose medical information that affects readiness (see DoD Instruction 6025.19, "Individual Medical Readiness"). Testing outside the Military Health System is unlikely to include a clear description of this risk.

Moreover, there is increased concern in the scientific community that outside parties are exploiting the use of genetic data for questionable purposes, including mass surveillance and the ability to track individuals without their authorization or awareness.

Until notified otherwise, DoD military personnel are advised to refrain from the purchase and/or use of DTC genetic services.

Handwritten signature of Joseph D. Kernan in black ink.

Joseph D. Kernan
Under Secretary of Defense for Intelligence

Handwritten signature of James N. Stewart in black ink.

James N. Stewart
Assistant Secretary of Defense for Manpower
and Reserve Affairs, Performing the Duties
of the Under Secretary of Defense for
Personnel and Readiness



Background (3/4)

- Ethical Issues Facing Military Clinicians
 - Use of Genetic Testing in the Military Service
 - Responding to Service member DTC Results
 - Reporting Genetic Testing to Chain of Command



Background (4/4)

- Service members must submit health care reports from non-Military Health System providers/organizations... but enforcement is difficult
- Individuals must weigh the benefits and costs of disclosing tests or results
- Advances will challenge the DoD to determine the role of genetic testing in recruitment, advancement, and selection



Way Ahead

- Kickoff meeting Winter 2020/2021
- Subject matter experts will brief the Subcommittee on:
 - Current DTC genetic testing companies & methodology
 - Healthcare privacy and security
 - Genetic testing policy best practices
- Planned decision brief at the May 2021 DHB Meeting

Questions ?