

Ethics watch

THE G.I. GENOME: ETHICAL IMPLICATIONS OF GENOME SEQUENCING IN THE MILITARY

The JASON Defense Advisory Panel (JASON), an independent group of scientific advisers to the US Department of Defense (DoD), recently published a report that highlighted the increased sophistication and cost-effectiveness of genome-sequencing technologies and recommended the creation of the necessary infrastructure to perform genetic research on military personnel¹. This report is the latest evidence of the DoD's increased interest in the use of genome-sequencing technologies to improve the health and effectiveness of the armed forces; in addition to collecting DNA samples for the identification of remains, the military performs genetic testing for sickle cell anaemia and glucose 6-phosphate dehydrogenase (G6PD) in order to protect at-risk individuals from specific environments or occupations that may trigger adverse effects². Although the US military appears to be at the forefront of using genetic information in its operations, there are signs that other militaries are also interested in collecting genetic data from service members.

The potential benefits of genomic research may be significant, but military practices surrounding the use of genetic information have invited controversy in the past. Genetic tests for congenital disorders have led to the denial of military medical benefits to some US service members, prompting other military personnel to decline genetics tests that may have concrete benefits to their health and effectiveness³. When the DoD's mandatory DNA biobank was established in 1991, its use was statutorily limited to the identification of remains. But the use of this biobank has since been broadened to allow the identification of potential suspects in some military and civilian criminal investigations⁴. Furthermore, DNA samples are not always destroyed when an individual leaves the military, so the repercussions of sharing genomic information may follow service members into civilian life⁵.

Efforts to further expand military use of genetic data for research purposes must therefore be viewed with some caution. Military personnel are an inherently vulnerable population from a research perspective; the military's framework of obedience, although essential to its function, calls into question whether informed consent is truly voluntary in these circumstances⁶. In the United States, submission of a DNA sample for forensic purposes is mandatory upon enlistment;

because no consent was given, these samples are now ineligible for research purposes. Genomic research must therefore be strictly separated from the use of genetic information for operational purposes, such as tailoring deployment to account for congenital environmental vulnerabilities. Use of these samples could be expanded for research purposes if consent were obtained, but consent would be required from each individual with a sample currently stored in the database (or from their next of kin). It is unclear whether this process would be more or less arduous than obtaining research-specific samples.

Preliminary data suggest that many veterans approve of genomic research on military populations, so recruitment of samples for research purposes might generate high rates of participation⁷. However, any policy on the DoD's conduct of genomic research must take into account the institutionalized nature of the armed forces. Researchers should design a participation policy that offers no medical or professional disadvantage to the individual in the event of non-participation and makes clear the potential privacy implications.

In addition, genetic information may considerably affect perceptions of an individual's health and professional capacity, increasing the potential for discrimination and stigmatization. To avoid such outcomes, the US Congress passed the Genetic Information Non-Discrimination Act of 2008 (GINA), which denies access to, or use of, genetic information by the civilian employment and health insurance spheres⁸. Although some DoD policies have likewise been modified to address the impact of genetic testing on health care and disability benefits, US military members are not covered under GINA⁹. Indeed, it is doubtful that the kind of information quarantine that is attempted by GINA would be possible in the military context. For service members (and their families), the DoD acts in the role of employer, medical insurer, (potential) researcher and social welfare provider, and it would be difficult (and counter-incentivized under current policies) to prevent genetic information obtained in one of these spheres from being used in another.

These considerations may also apply to social and interpersonal stigma. Research has



shown that stigma surrounding mental health disorders in the military has a deleterious effect on the soldiers' willingness to seek care for psychiatric conditions¹⁰. Similarly, the display of pertinent genetic information — such as sickle cell vulnerability — on dogtags, and its role in assignment and promotion decisions may benefit the health of the individual soldier¹ but may also generate stigma and affect individual career outcomes.

To avoid such institutional and interpersonal discrimination, the DoD should maintain no direct links between genomic research data and information that could reveal individual service members' identities until relevant genetic findings are ready for use on a military-wide basis. If actionable discoveries are made using these data, military-wide screening could be performed under policies that are specifically designed to minimize the potential for unjust outcomes.

Given the distinctive circumstances of military service, it is easy to see why JASON anticipates that genomic research may have particular benefits for military populations. Although we share their optimism, it is important that genomic research programmes within the DoD be carried out with careful attention to the singular ethical dilemmas that arise from the military's unique position.

Megan Allyse, Lauren C. Milner and Mildred K. Cho
Center for the Integration of Research on Genetics and Ethics, Stanford Center for Biomedical Ethics,
Stanford University, 1215 Welch Road,
Modular A, Stanford, California 94305, USA.

e-mails: megand@stanford.edu; lmilner@stanford.edu; micho@stanford.edu

The authors declare no competing financial interests.

REFERENCES ¹JASON Defense Advisory Panel. The \$100 genome: implications for the DoD. *Federation of American Scientists* [online], <http://www.fas.org/irp/agency/dod/jason/hundred.pdf> | ²US DoD. HA Policy 97-018: memorandum for Secretaries of Military Departments Assistant Secretary of Defense (Force Management Policy), subject: sickle cell testing. *Tricare* [online], <http://www.tricare.mil/policy/fy97/sckl9718.html> (1996) | ³Kaplan, K. U. S. military practices genetic discrimination in denying benefits. *LA Times* [online], <http://articles.latimes.com/2007/aug/18/science/sci-genes18> (18 Aug 2007) | ⁴Ham, P. *Army Lawyer* **27-50-363**, 1-19 (2003) | ⁵Kipnis, K. in *Stored Tissue Samples: Ethical, Legal and Public Policy Implications* (ed. Weir, R. F.) 329-344 (University of Iowa Press, Iowa City, 1998) | ⁶McManus, J. et al. *Acad. Emerg. Med.* **12**, 1120-1126 (2005) | ⁷Kaufman, D. et al. *Genet. Med.* **11**, 329-337 (2009) | ⁸Baruch, S. & Hudson, K. *Am. J. Hum. Genet.* **83**, 435-444 (2008) | ⁹US DoD. Instruction 1332.38: physical disability evaluation. *Defense Technical Information Center* [online], <http://www.dtic.mil/whs/directives/corres/pdf/133238p.pdf> (2006) | ¹⁰Britt, T. W. *Mil. Med.* **172**, 157-161 (2007)