FORCE
Facing Our Risk of Cancer Empowered
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Thank you for the opportunity to submit comments on behalf of FORCE: Facing Our Risk of Cancer Empowered and the millions of Americans affected by hereditary cancers.

OBJECTIVE
We are disappointed that the Proposed Objectives for Inclusion in Healthy People 2030 eliminated the two hereditary cancer Developmental Objectives contained in the HP2020 plan and request that they be added to the Healthy People 2030 objectives:

- Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling
- Increase the proportion of persons with newly diagnosed colorectal cancer who receive genetic testing to identify Lynch syndrome (or familial colorectal cancer syndromes)

These genomics topic areas and objectives aimed to reflect the increasing "evidence supporting the health benefits of using genetic tests and family health history to guide clinical and public health interventions" and "scientific evidence supporting the health benefits of using genetic tests and family health history to guide clinical and public health interventions." There is a need and opportunity to build upon these objectives as new research emerges on the benefits of identification of people with inherited cancer risk to improve health outcomes.

OBJECTIVE RATIONALE
Despite increases in BRCA mutation and Lynch Syndrome testing, most high-risk individuals remain unidentified. Equally concerning is the fact that many people undergo genetic testing without the benefit of genetic counseling to ensure that the right test is ordered, results are interpreted accurately, and implications for the patient and his or her family are fully explained. The world of genetics is advancing rapidly, the cost of testing has become more affordable, and we are testing for many more genes than in the past. The need for genetic counseling has never been more crucial.

The HP2020 objectives note that two independent panels—the U.S. Preventive Services Task Force and Evaluation of Genomic Applications in Practice and Prevention Working Group—recommend genetic counseling and testing for these hereditary cancer syndromes. This is further supported by guidelines from respected organizations including the National Comprehensive Cancer Network, American College of Obstetricians and Gynecologists, Society of Gynecologic Oncology, American Society of Clinical Oncology, American Cancer Society, etc.

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As stated, Developmental Objectives represent high priority issues that do not yet have the reliable baseline data needed to make them Core objectives, and have evidence-based interventions available. The hereditary cancer objectives contained in the HP2020 Plan continue to meet this criteria.

Additionally, there is growing evidence that multigene panel testing cancer risk assessment yields findings likely to change clinical management for substantially more patients than does Lynch or BRCA1/2 testing alone. Expanding the genomics objectives to cover testing for multiple gene mutations associated with hereditary cancer would benefit a broader population.

While hereditary cancers are only a subset of all cancers, they impact entire families and multiple generations. Tests for germline mutations associated with increased risk of cancer have the potential to improve health outcomes for these families through improved risk prediction, prevention, earlier diagnoses, better treatments and prognoses. The genomics objectives support Core objectives related to breast, colorectal, prostate and other cancer. As such, they are ideal for a Healthy People initiative.

In addition to the objectives for identifying people with Lynch Syndrome and BRCA1/2, there is even greater value in expanding the genomics objectives to include increasing uptake of guideline recommended cancer risk management. The shift from identification to risk-based screening and prevention will further the objectives of attaining better quality of life free of preventable disease, disability, injury, and premature death. In order to achieve health equity, eliminate disparities, and improve the health of all groups, we must recognize and encourage the adoption of evidence-based, risk-based preventive strategies for those who are born with an inherited mutation that increases their risk of cancer.

PROPOSED DATA SOURCE

To measure success, commercial laboratories could report test results as a means of measuring an increase in the number of patients who are receiving genetic testing, health systems and health insurers could report the number of patients receiving genetic counseling and/or testing, and guideline-recommended screening and prevention interventions based on electronic health records and claims data. Regarding Lynch Syndrome, tumor registries have a site specific field for microsatellite instability that could be used to track the numbers of colorectal cancer patients being screened for Lynch Syndrome at the time of diagnosis. Another method of tracking progress would be to add a field to collect data on relevant genetic test results in SEER and all cancer registries. There are some pilot studies aimed at linking cancer registry data with genetic laboratory testing data. If this is viable, it will readily facilitate tracking moving forward.