findings, such as the wide disparities in breast and prostate cancer rates, are poorly understood, and call for epidemiologic studies to provide insight into the observed differences.

"The data may raise questions about why things are changing — or aren't changing — for certain groups," said Benjamin F. Hankey, Sc.D., chief of NCI's Cancer Statistics Branch. "Monitoring these groups is important because each has a unique culture and lifestyle as well as possibly unique genetic factors," which may influence their cancer risk.

SEER covers about 14% of the overall U.S. population, but by design includes substantially larger percentages of minority populations: 78% of Hawaiians, 60% of Japanese, 49% of Filipinos, 43% of Chinese, 34% of Koreans, 31% of Vietnamese, 27% of American Indians, and 25% of Hispanics.

The tremendous influx of Hispanics into the United States during the last decade led SEER to increase coverage of this ethnic group by adding, in 1992, Los Angeles County and the San Jose/Monterey area of California (see News, Jan. 3, 1993). Data are presented separately for the white Hispanic and total Hispanic populations. (Hispanic is an ethnic, not a racial, identifier, and Hispanics may be persons of any race.) Hankey said that in the future, SEER will make available further information about geographic variation among Hispanics' cancer rates, which might be expected to vary in part because Hispanic populations in different areas of the United States have different mixes of national origin.

### Centers on 1990

Calculating cancer rates for smaller minority groups is problematic, Hankey said, partly because — in contrast to data on blacks and whites — population estimates are not generally available for these groups in between-census years. The new report "centers" on 1990 because that year's census provides population estimates on which cancer rates can be based.

In addition, the smaller populations of these groups make their cancer rates somewhat less reliable than rates calculated for larger groups. Some rates are missing from the monograph because there were fewer than 25 cases on which to calculate rates — too few to allow for confidence in their reliability.

Kolonel said the monograph is the first of a planned series of special SEER publications designed to be useful to "the educated layperson" as well as researchers. Topics of upcoming monographs are expected to include cancer survival in minorities, childhood cancer, and major individual cancer sites.

"We deliberately worked to make it eye-appealing as well as useful to people who may be a little less sophisticated about statistics," he added.

### Hub of the Network

Forming the initial hub for the network, participants suggested, would be NCI's 28 comprehensive cancer centers, which could then branch out to include other institutions that specialize in genetics research and counseling.

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**NCI Plans National Cancer Genetics Network**

By the end of its first, day-long meeting, the newly formed Cancer Genetics Working Group had hammered out a plan of action to guide the National Cancer Institute toward the creation of a cancer genetics network for the nation.

Convened by NCI Director Richard Klausner, M.D., the group of intramural and extramural scientists voted to set up three subcommittees to define the network's mission in the months ahead.

As envisioned by workshop participants, the NCI-sponsored cancer genetics network would be a cooperative effort between NCI and researchers around the country where appropriate use of genetic testing (for cancer predisposition) is offered within a research setting. Individuals participating in the network would also have access to counseling and up-to-date clinical information, along with the opportunity to take part in intervention studies.

### Dr. Richard Klausner

Dr. Richard Klausner

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**NEWS 579**
In the days ahead, the institute will develop the "architecture and process" by which such a network can be put into place relatively quickly, Klausner said. "We need a system to grow as we learn."

The workshop, which was held in the first week of April, had been planned for months, but the group's first meeting could not have been more timely.

Just 4 days earlier, a private commercial institute announced it would offer a genetic test for a breast cancer gene whose mutation predisposes some women to breast and ovarian cancers.

While some researchers praised the move, others condemned as premature the decision by Genetics and I.V.F. Institute in Fairfax, Va., to offer testing for the BRCA1 gene in that there is still uncertainty about what a positive test — even for some members of high-risk families — may mean. Moreover, the effectiveness of existing prophylactic treatments is also unclear.

"Certainly, the rationality of using [certain] treatments is one of the most pressing issues of clinical oncology today," said Ken Offit, M.D., director of the Clinical Genetics Service at Memorial Sloan-Kettering Cancer Center in New York and a member of the working group. Offit added that the demand for genetic testing will be driven by the oncology community, particularly radiologists and surgeons, who along with patients, are "awaiting guidance."

Some Screening

Whether the network will service anyone who wants a genetic test, however, seems unlikely, noted Ruthann Giusti, M.D., an NCI scientist who is the working group's executive secretary. "At least initially, there will probably be some screening process in place," she said, "but this is not yet defined."

Other issues, which the subcommittees will address, include how to set up a national system that meets research needs without compromising patient confidentiality; how to set up longitudinal studies that tie in with existing NCI efforts; and how to develop educational materials for health care professionals outside the oncology community who may treat patients who self-identify as being at high risk for certain cancers.

Additionally, a uniform thread running through all of these discussions will be how to pay for the network and whether managed care groups and other third-party payors should be brought into the loop for discussions.

But there was one thing on which everyone agreed: the need to push forward as quickly as possible.

"The interest [in genetic testing] is likely to grow, not shrink over time," predicted Francis Collins, M.D., Ph.D., director of the National Center for Human Genome Research at the National Institutes of Health and a member of the working group.

"Even though we don't know what that demand will be, we need to move forward now," Collins said.

— Susan Jenks

President Issues Proclamation Declaring April Cancer Control Month

In recognition of Cancer Control Month, which was April, President Bill Clinton issued the following proclamation:

The White House
Office of the Press Secretary
March 29, 1996

Cancer Control Month, 1996

By the President of the United States of America

A Proclamation

Research and the prompt application of research results have proved to be the strongest weapons we have against cancer. And we are making great strides in the study of this deadly disease. Indeed, the understanding of the processes by which a normal cell is transformed into a cancer cell is one of the great achievements of cancer research. Genetic studies are leading to better understanding of many cancers and improving our ability to intervene and stop their spread.

While the implications of some findings are still unclear, we know that further progress hinges on continued scientific inquiry, and we understand that basic research must remain a national priority. In addition, all of us can act on information already at hand to make lifestyle choices that reduce the risk of developing cancer.