Frequently Asked Questions

What is the purpose of CPS-3?
The goal of CPS-3 is to better understand the factors (lifestyle, environmental, genetic) that cause or prevent cancer and, ultimately, to help eliminate cancer as a major health concern for future generations.

What does study participation involve?
Enrollment is a simple process. At your enrollment appointment, you will be asked to sign an informed consent, complete a survey packet, and provide a waist circumference measurement and a small blood sample (similar to a doctor's visit). The blood sample will be taken by a certified, trained phlebotomist and your appointment will last approximately 30 minutes. You will be asked to complete mailed questionnaires every few years to update lifestyle, environmental, and medical information.

Who is running the study?
CPS-3 is funded and managed by the American Cancer Society Department of Epidemiology & Surveillance Research (Analytic Epidemiology program). The Analytic Epidemiology program conducts, analyzes, and publishes original research on the causes and prevention of cancer utilizing these large follow-up studies.

How long will the study last?
Participants will be followed for at least 20 years. This means that once you are enrolled we will be contacting you periodically with mailed surveys for you to answer. While you may be in the study for many years, we expect the amount of time it will take you to answer a survey to be minimal (about 45 minutes for the follow-up surveys).

Who is eligible to enroll?
Men and women between the ages of 30 and 65 who have no personal history of cancer and are willing to make a long-term commitment to the study.

Why is there an age range from 30-65?
An important part of maintaining the scientific validity of this study is being able to follow individuals over time. Generally young adults in their 20's tend to be more transient and it becomes more difficult to follow these individuals. For individuals over the age of 65, much of the relevant time period for exposures of interest (such as during early and middle adult years) has to be recalled and remembering events, behaviors, or other lifestyle information from many years ago with accuracy can be difficult. For these reasons, we are looking for individuals between the ages of 30 and 65 and will follow them while collecting relevant lifestyle, behavioral, and medical information moving into the future.

Why not study individuals who have had cancer?
Since the goal of CPS-3 is to better understand ways to prevent cancer, it is important to begin with individuals who have never had cancer. Once a person has had cancer, the body has been affected by the disease, treatment, and/or lifestyle changes. For this reason it is difficult to collect certain kinds of information and study how to prevent the disease. Additionally, various factors in the blood may be altered due to treatment. Enrolling individuals who have never been diagnosed with cancer will enable us to study how to prevent the disease.

2012 open enrollment

Why do you need people to be willing to make a long-term commitment to CPS-3?
There are two equally important pieces to building a study like CPS-3. The first, and more obvious piece, is getting at least 300,000 individuals to enroll into the study. The second piece is to keep these individuals in your study over a long period of time. Large-scale studies like CPS-3 are scientifically valid only if you can successfully track and "follow" your participants over time. So, maintaining contact with participants is critical. We need individuals who not only meet the eligibility criteria, but also are willing and able to make the long-term commitment to the study.

Why is the goal to enroll at least 25% minority (racial and ethnic) representation?
To determine whether risk factors for cancer are different across various racial/ethnic groups, we need to enroll men and women across a wide range of racial/ethnic groups as well as across a range of ages.

Will translated materials be available?
Materials will be translated to Spanish only.

Will every state have CPS-3 enrollment available?
While we will be enrolling in every division of the American Cancer Society within the next five years, we will not enroll in every state in the US. This decision was based on various factors including quality of state cancer registries, population density, and proximity of the study laboratory partner facilities. The CPS-3 website, **www.cancer.org/cps3** will post the most up-to-date enrollment dates and locations.

Do I have to live in the U.S. to be eligible for CPS-3?
Due to difficulty in following individuals for the length of the study, individuals must live in one of the following countries or territories to be eligible for enrollment: United States, Puerto Rico, and Guam.

Who makes sure this study is safe and scientifically sound?
There will be ongoing peer review of CPS-3 by cancer researchers from many prominent university and research institutions. Review and oversight by the Emory University IRB (Institutional Review Board) continues throughout the study. When a study has completed active enrollment, the IRB continues to provide oversight while investigators analyze questionnaire and biological data.

What is an Institutional Review Board?
An Institutional Review Board (IRB) is a research oversight committee charged with assuring, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of humans participating as subjects in approved research studies based on the ethical principles of the Belmont Report.

What is the Belmont Report?
In 1974 Congress passed the National Research Act which created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission wrote the Ethical Principles and Guidelines for the Protection of Human Subjects of Research (commonly referred to as the Belmont Report). The Belmont Report contains the ethical principles upon which the federal regulations for protection of human subjects are based.

How will you use all of my information?
We begin the study by collecting information on various exposures from individuals who do not have cancer and we continue to update this information over time. As cases of cancer or other diseases develop, we will compare those participants who develop cancer with those participants who do not. By doing so, we are able to understand the differences (in lifestyle, environment, and genetic factors) between people who get cancer and those who do not, what the likely risk factors are for cancer, and how to best prevent disease in the future.

Will I ever have to provide medical records?
If you are diagnosed with cancer while you are still participating in CPS-3, we will ask you for written permission to seek more information about your diagnosis and treatment from your doctor and from your medical record. At that time, you can agree to give us permission or not. Since risk factors for cancer may differ by various pathologic characteristics (like tumor location, tissue type, etc.) the best source for accurate information on specific tumor features is the medical record.

Why do I have to provide my social security number?
We understand that social security numbers are private and many individuals are worried about sharing this information. However, social security numbers are very important in long-term follow-up studies like CPS-3. We use them to link with important data sources, such as cancer registries and death certificates, to learn who in the study has developed cancer or who has died. We will never willingly share this number with anyone and only key study personnel will have access to use it for purposes related directly to CPS-3. These personnel are part of the scientific research team and understand the importance of protecting your privacy.

Will my information be kept confidential? How will this be done?
Yes. Every effort will be made to protect the identity of the participants in this study. All of the study staff sign confidentiality forms and undergo training in research ethics. When your data are collected, they are labeled with a unique identification number. After your data are collected, your blood samples, surveys, and other study materials are stored separately from all personal identifiers, such as your name, address, phone number, and social security number. All study materials will be stored in a locked facility and secured computer files, and your personal contact information will be kept in separate files accessible only to a limited number of CPS staff. This information will not be shared with anyone, including other staff at the American Cancer Society, unless they are directly involved in managing CPS-3.

Why am I completing a "menstrual" postcard (for women only)?
Hormones levels are strongly related to the development of many types of cancer in women (such as breast, endometrial, and ovarian cancer). A woman's hormone levels vary greatly during the monthly course of her menstrual cycle (or period). For this reason, it is critical for us to understand where in the monthly menstrual cycle a woman is when she provides her blood sample. We obtain the first date of the last period (on the enrollment survey) and also the first day of the subsequent period (through this postcard) so that we can pinpoint the exact date of your cycle when blood was drawn. This postcard will be mailed to each participant so that you can indicate when your next cycle begins and return it to the Epidemiology Department.

What if I no longer have periods? Do I still have to complete the postcard (women only)?
No. If you no longer have menstrual periods, you do not have to complete your mailing address on the postcard.

Why is a waist measurement required?
Many conditions, such as insulin resistance, diabetes, and other metabolic conditions, are highly related to waist circumference. Many of these conditions are also related to the development of cancer. Thus, getting this simple waist measurement will provide very important information to researchers in the future.

What if I don't want to give this measure, can I still be in the study?
Providing a waist measurement is part of the enrollment process. The more complete the data you provide us about yourself, the more valuable our research resource becomes.

Why is a blood sample required?
We need a blood sample to measure things such as hormones, nutrients, vitamins, chemicals, metals, and genetic factors that may be related to your risk of developing cancer. Questionnaire data provide a detailed picture of your lifestyle and environment, but the most accurate picture of your actual exposures or susceptibility to disease may come from what we can measure in your blood. It is important that we collect this sample when you first enroll in the study so that a new health problem does not alter the levels of anything we measure.

What if I don't want to give a blood sample, can I still be in the study?
Providing a blood specimen is part of the enrollment process. The more complete the data you provide us about yourself, the more valuable our research resource becomes. Without your blood sample, we are unable to examine any blood or genetic measures in relation to cancer risk.

What happens to my blood sample?
All blood samples will be frozen and stored in a secured biorepository facility. Samples will be analyzed as cancer cases occur.

Why don't you do all of the blood tests at the start of the study? Why do you need to store my blood?
At the start of the study, we do not know who may develop cancer. As cancer cases occur, we will study measures in the blood that may be important in cancer development. We would also like to take advantage of advances in science and technology as well as explore potentially new hypotheses in the future and having blood samples stored will allow us to do the tests that are most likely to give us new information about cancer development.

Phlebotomists often times have difficulty drawing my blood, will I be dropped from the study if they can't get my blood?
No. Per our scientific protocol, trained phlebotomists will make two attempts to withdraw blood from a study participant after which they will stop trying. If the phlebotomist is unable to draw blood, you still will be enrolled in the study.

Is there any risk involved with this type of blood collection?
There is limited risk with this type of collection. Collecting blood from a vein in someone's arm is a standard medical procedure; however, there is a small risk of some discomfort or bruising at the spot where blood is withdrawn.

Will I be notified of any results from tests done on my blood?
No. By enrolling in CPS-3, you are donating your blood sample for research purposes only. You will not be informed of any of the results of any tests that may be performed using your blood sample. Reasons for not sharing individual results include: testing is not performed in certified clinical labs, and testing is not intended to be used as a diagnostic test or to make decisions about your medical care. Although, we will not be able to provide you with your individual test results, we will share results from our overall analyses with all study participants through newsletters, e-mail, articles on our website or other means.

Do I need to fast prior to the blood draw?
No, this is not a blood draw for diagnostics tests, no fasting is necessary. Additionally, you will indicate with one of the questions the last time you ate.

Why would I want to participate in this research study?
Most people who participate in research studies hope they will contribute to a better understanding of how to prevent disease. For CPS-3, this knowledge will help reduce the burden of cancer for this and future generations.

Will it cost me anything to participate in the study?
There are no costs to you other than your time for participating in the study. Costs for the blood draw, survey materials, and postage will be paid by the American Cancer Society.

Will I get paid to participate in the study?
You will not receive any direct payment from participating in this study. However, by taking part, you will help us learn more about the causes of cancer and other diseases, and perhaps help us find ways to prevent cancer in the future.

Will I be asked to take any pills or perform any other medical procedures besides the blood sample?
No. We will never ask you to take any medications or pills. Once you have donated a blood sample you will not be asked to complete any other medical procedures.

I am pregnant can I participate?
Yes, you may participate.

I have just had surgery or have any medical condition besides cancer, can I participate?
Yes, you may participate.

Can I still be in the study if I develop cancer?
Yes. As cases of cancer or other diseases develop, we will compare those participants who develop cancer with those participants who do not. By doing so, we are able to understand the differences (in lifestyle, environment, and genetic factors) between people who get cancer and those who do not, what the likely risk factors are for cancer, and how to best prevent disease in the future. We also want to learn if environmental, lifestyle, and genetic factors influence treatment outcomes, survival, and quality of life following a cancer diagnosis. It will be important for us to follow all participants, including those who develop cancer, for the full length of the study.

How do I enroll in CPS-3?
Visit the CPS-3 website at **www.cancer.org/cps3** for a full list of enrolling locations or call toll free, **1-888-604-5888**.

What happens if I move or change my phone number or email address while I'm in the study?
We want you to let us know about changes in your contact information as soon as possible. You can call us toll free at **1-888-604-5888** or email us at **cps3@cancer.org** to report any changes. We also will give you the opportunity to provide new contact information every time we mail a follow-up questionnaire.

How will I get results of the study?
It is important to us that you learn results from CPS-3 as soon as possible. We will send you annual newsletters with highlights of study results. CPS-3 results also will be published in scientific journals, and we will post these on the American Cancer Society website (**www.cancer.org**), and provide links to the articles.

Where can I find out more about risk factors, diagnosis, and treatment for cancer?
You can contact the American Cancer Society by calling **1-800-ACS-2345** or by visiting the American Cancer Society website at **www.cancer.org**. Cancer information specialists are available 24-hours a day 365-days a year to answer questions about diagnosis, treatment, statistics, financial assistance, and support programs. Spanish services are available.

How can I learn more about CPS-3?
Please visit our website at **www.cancer.org/cps3**, email us at **cps3@cancer.org**, or call our toll free number at **1-888-604-5888** for more information.