CONSENT TO PARTICIPATE IN THE RESEARCH PARTICIPANT REGISTRY (Pitt+Me)

What is the purpose of this Research Registry? A research registry is a collection of individuals interested in being told of research studies of which they might like to take part. Part of UPMC’s mission is to provide outstanding patient care by learning from research studies. Because you are a patient at a UPMC facility age 18 or older, we are inviting you to participate in this research registry.

How does this registry work? If you join the registry, you will be giving your permission:
(1) for UPMC and University of Pittsburgh researchers to use all of your past, current and future medical record information for retrospective research studies or to see if you are eligible for any research studies, and
(2) to allow members of the Research Participant Registry Office to contact you to find out if you are interested in learning about research studies for which you appear to qualify. This office will also send you periodic mailings that will provide you with educational information about health, about interesting research findings, and about research studies that are available. Some of these studies are clinical trials, which are research studies looking at new ways to diagnose, prevent, or treat medical diseases or disorders. Some of these research studies may have something to do with a disease or condition that you have, and some studies will need healthy individuals to participate. You do not have to participate in any research study that you hear about as a member of the registry.

How will the privacy of my medical record information be protected? Several procedures have been put into place to protect the privacy of your medical record information. Only members of the Research Participant Registry Office and staff in the Research Conduct and Compliance Office will have access to your identifiable medical record information, and these individuals will be required to sign a privacy agreement. However, just as with the use of your medical information for health care purposes, we cannot guarantee its privacy.

Are there any risks or benefits associated with participation? There are no physical risks associated with agreeing to participate in this registry. There is a possibility of a breach of confidentiality, as described above, but we have safeguards in place to minimize that. There may be no direct benefits to you, but Registry participants will have access to educational information regarding their health. There are no costs or payments associated with participation in this Registry.

May I withdraw, at a future date, my permission for participation in this Research Registry? Yes. To do so, you can contact the Research Participant Registry Office by phone (1-866-438-8230), or at the address listed above.

Your participation is completely voluntary and your decision whether or not to participate in this Registry, or to later withdraw from it, will not affect your current or future medical care at UPMC. Your medical record information will be reviewed until you withdraw your permission for participation in this registry.

If you would like additional information, you may contact the Research Participant Registry Office at 1-866-438-8230. Questions about your rights as a research participant will be answered by the Human Subject Protection Advocate at the University of Pittsburgh IRB Office (1-866-212-2668).

I do wish to be included in the UPMC Research Registry and agree to allow the use and disclosure of my medical record information, as described above.