

An Ambitious New Precision Oncology Research Program, TakePART-NW, Launches at Fred Hutch

Patients who opt in to TakePART-NW may help solve the mysteries of cancer and other diseases.

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Fred Hutch Cancer Center aims to enroll 200,000 patients over the next 10 years in a new research program called [TakePART-NW](#) (Patients and Research Together-Northwest) to improve screening, prevention and treatment for cancer and other diseases. The program, led by the [Stuart and Molly Sloan Precision Oncology Institute](#), launched at the end of March, when patients at Fred Hutch's South Lake Union Clinic began seeing an invitation to participate when they signed in to the MyChart patient portal. Over time, the TakePART-NW team plans to expand the program to all Fred Hutch clinic locations as well as UW Medicine sites and other facilities around Washington state.

TakePART-NW is part of Fred Hutch's ongoing effort to develop a world-leading program in precision oncology. Precision oncology is personalized care that's tailored not just to a patient's cancer type or even subtype but to their specific tumor.

"This program has the potential to help us discover better ways to prevent cancer, detect it early and treat it effectively, including the most advanced, dangerous forms of the disease," said [Peter S. Nelson, MD](#), the institute's director and primary investigator for TakePART-NW. Nelson holds the Stuart and Molly Sloan Precision Oncology Institute Endowed Chair.

Getting to be part of the solution

By choosing to join the program, a patient agrees to have tissue, blood or other biological samples that are left over after their regular testing and treatment stored for future use in research. Researchers will also have access to the patient's de-identified health information; details that could reveal who the individual is will be removed or hidden. Participants may opt in or out of giving an additional tube of blood or a sample of saliva for research use, and they can choose whether to receive any results specific to them that researchers might generate.

"Our goal is to improve the health of individuals, their families and their communities and to make

cancer a thing of the past. The way we're going to be able to do this is through research, and the most productive and effective research depends in part on the people in our community being willing to participate," said Nelson. "Even with all our advances, cancer remains a leading cause of mortality and morbidity. We hope our patients will see TakePART-NW as an opportunity to be part of the solution."

Tonia Bartz, who considers herself a "cancer thriver," shares this hope. She's one of many volunteer members on the Fred Hutch Precision Oncology Community Advisory Board who guided the team that developed TakePART-NW. Along with other board members, Bartz provided input on the materials Fred Hutch created to explain the program to eligible patients. She's enthusiastic about the possibilities.

"There's so much potential in having this database of samples for the future of cancer treatment and prevention," said Bartz, a holistic wellness coach. "For many patients, it doesn't take a lot of extra work, and knowing how many people it can potentially help, in my opinion, it's a small ask for a big reward. Participation is a way for us to take initiative and help ourselves as well as our friends, those who we love and those around us in our communities."

How the samples can be used

While the initial focus is cancer, the program could expand to investigate other conditions, such as dementia, neurodegenerative or cardiac problems, or infectious diseases. Researchers from Fred Hutch, UW Medicine and other institutions will be able to request use of the samples and de-identified health information for specific projects. An independent ethics review board will evaluate and approve requests.

"The potential types of research are broad. We can't predict yet the amazing innovations or ideas researchers will have. But there are strict guidelines researchers will need to follow to be granted access," said Nelson. "When patients give consent for researchers to use their materials, they can feel confident that we'll be good stewards. Anything done with their samples will undergo very rigorous review to make sure it's ethically and legally appropriate, that it's being used for a higher purpose, and we'll safeguard their data."

A legacy of hope

Janet Turner, another member on the Community Advisory Board, is a retired social worker with [chronic lymphocytic leukemia](#). She encourages fellow patients to participate — and she also understands if some feel unsure at first, especially given the history of mistreatment and underrepresentation of people of color in scientific studies.

"I had to think long and hard about this program because I'm a person of color, so when I think of research, I think of the trauma that has been imposed on people of color," she said, acknowledging that concerns around trust are valid. "It wasn't an easy decision for me. But I see

the value in people from a wide variety of cultures being represented. I know my participation could have a big impact on future generations.” She hopes other patients will participate too as a way to “leave a legacy of hope.”

Informed consent goes digital

One of the many layers of protection in research is informed consent, the process of giving key details about a study or program to someone who might participate so they can decide whether to join. At Fred Hutch, this often takes place face to face: A physician or a member of the research team explains the research study or project — including the purpose, risks and benefits — to a patient in person and answers their questions. In order to enroll, a participant then signs an informed consent form.

TakePART-NW streamlines the informed consent process for patients by moving it online. Through [MyChart](#), interested patients can access a set of brief videos to learn about the program. Then they can complete a questionnaire, saying “yes” or “no” to each aspect: allowing use of their leftover tissue and de-identified clinical data, giving an additional tube of blood or a saliva sample, and getting information back from researchers. The [TakePART-NW webpage](#) also offers written details for anyone who wants to know more.

“Our consent process is designed to be convenient for patients,” said Nelson. “They can do it from home whenever works for them. It doesn’t need to take time out of their visits with their care team,” though they’re welcome to ask their Fred Hutch providers about it. Members of the TakePART-NW team are also available to answer patient questions by telephone at [206-606-6045](tel:206-606-6045) or by email at takepartnw@fredhutch.org.

A shift toward greater transparency

Taking care to inform potential participants, answer their questions and request their permission is important in modern research. That hasn’t always been the case, said Nelson, citing the now-famous example of [Henrietta Lacks](#), a young Black woman whose cervical cancer cells were collected at Johns Hopkins in 1951 and used for research without her knowledge or consent.

“For TakePART-NW, we want individuals and their families and communities to know they can say ‘yes’ or ‘no’ and consciously, proactively decide if they want to be part of the project,” said Nelson.

He’s hopeful that the people who choose to enroll will accurately reflect the full range of patients Fred Hutch sees, including a variety of racial and ethnic backgrounds. Broad participation could enable researchers to better understand differences in cancer incidence and outcomes between groups. To help with this, the team is exploring ways to offer the informed consent process in several of the languages most commonly used by people eligible to participate. They hope to add this capability in the future.

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