

October 9, 2017. Janie Appleseed Network announces a new pilot program to teach families how to use personal health record technology. Westerly, RI.

Janie Appleseed Network announces a new pilot program to teach families how to use personal health record technology.

The pilot program will engage families in the use and development of an emerging class of health information technology systems aimed at giving consumers sovereignty over their personal health data. A personal health record system, or PHR, is a digital computer application that helps a consumer store and manage personal health data captured over time. A PHR helps a person collect and use past information to inform present and future health and care choices.

“It’s important for consumers to understand the difference between a PHR and a Patient Portal,” explains Janie Appleseed Network Executive Director Lisa Nelson. “A Patient Portal is a system that is controlled by a healthcare delivery organization. It gives a patient the ability to view and download information that exists in the care organization’s electronic medical record (EMR),” Nelson explains. “What does a patient do with that information once they download it?” she asks. “The idea behind this new class of system is to give consumers a tool they control—a place where the system and the information is theirs,” she explains.

“There’s a new role planned for patients,” says Nelson. “We need to prepare ourselves for the coming changes in healthcare.”

Patient empowerment is being touted as an important part of U.S. healthcare reform. For example, the 21st Century Cures Act (Cures Act), signed into law on December 13, 2016, is designed to help accelerate medical product development and innovation in healthcare. It elevates the importance of “real world evidence” and creates a way to apply useful and timely information used from observational studies, patient input, and anecdotal data so that healthcare can become more of a learning health system.

New “value-based care” payment models compensate providers for managing a patient’s health (fee-for-value) rather than providing care (fee-for-service). The goal is better health for individuals and reduced spending.

“The problem is, you can’t do value-based care if you don’t know what patients value,” says Nelson. “We need to modernize the way patients and their families communicate with the members of their care team. There needs to be technology that consumers and patients control—technology that allows consumers to document and exchange information about personal health goals, treatment preference, and care outcomes. Providers and Payers have systems that support their needs. Individuals need a system too. One that does what *we* want to do with our data, a system that helps *us* share and protect our health information. That’s what a PHR is designed to do, and that’s why we need consumer feedback when building a PHR.”

The Janie Appleseed Network Pilot will introduce approximately 30 families in the state of Rhode Island to this new type of PHR technology. Families will be selected from six different cohorts:

1. families with a new baby born after January 1, 2018 and before June 30, 2018,
2. families caring for a child with special needs,
3. families caring for an elderly parent,
4. families with a family member with a chronic disease,
5. families with a family member with substance addiction challenges,
6. families with no major health issues and actively focused on staying healthy.

One family member will be enrolled in the program and be trained to enable use of the PHR technology within the entire family. The program enrollee will attend a technology training “boot camp” and then attend monthly feedback sessions to report on her or his experience using the PHR technology within the family. The subscription service for the PHR technology, called MyPHD Wellness Manager, will be provided to participating families at no charge during the pilot.”

“The pilot is funded by donations through a Go Fund Me campaign,” explains Nelson. “Janie Appleseed Network is a non-profit 501 c 3 corporation. What we learn in Rhode Island will be helpful across the Nation. It will help everyone better understand what it means for consumers to develop 21st century health literacy skills. This type of program is integral to our mission to educate consumers about how to use health information technology in everyday life.”

Nelson also notes, “It’s not about getting people’s personal health data so we can use it to sell advertising. This pilot is organized *by the people, for the people*,” she says. “With organizations like Google and Amazon setting their sights toward supplying PHR technology, consumers need to beware,” she warns. “We need to teach people how to reign sovereign over their personal health data. It’s dangerous if we don’t.”

The Janie Appleseed Network pilot program begins January 1, 2018 and runs for a full year. Applications are being accepted in October and November, 2017. Selected participants will be notified this December. If you are interested in having your family participate in the pilot, apply by going to: <https://www.surveymonkey.com/r/JanieAppleseedPilot>.

About Janie Appleseed Network

Janie Appleseed Network engages consumers as an active force contributing toward the national goal of utilizing health information technology (HIT) to promote high quality healthcare, reduce unnecessary healthcare spending, and shift focus from treating illness to promoting holistic wellness.

The organization provides education and services to grow 21st century health literacy skills by cultivating adoption of consumer-controlled personal health records (PHRs). They provide education about the use of HIT to improve care and support wellness. They also advocate for inclusion of patients and families as equal participants within their care teams and raise awareness about personal health goals and preferences, and encourage personal choice in selecting care options.

The organization facilitates access to and awareness of communities supporting consumers to live healthier lives, and offers PHR services that help people increase their health literacy and better use and manage their personal health data (PHD). They foster adoption and use of PHR technologies as a basic life management tool, enabling people to control their PHD and have a say in how it gets used for research and public health initiatives.

Janie Appleseed Network maintains a library of stories that illustrate consumer views on meaningful use of PHRs and HIT. They secure grants and donations to reduce or subsidize the cost of consumer-controlled HIT tools and services with a vision of building a community of consumers interested in using HIT to improve their lives and the lives of others.

About Lisa R. Nelson

Nelson is a resident of Westerly, RI. She is a medical informaticist engaged in the creation of health information technology standards that make it possible to share health data between disparate technologies.

Nelson founded Janie Appleseed Network in 2014 after experiencing the challenges of becoming a caregiver and legal guardian for her aging parents. Navigating the aging process and the healthcare system for her Mom and Dad opened her eyes to the situation many will face as the Boomer Generation enters their twilight years.

Nelson's views about holistic health and balanced living influenced the vision to create new solutions that help people live differently, in ways that focus on staying healthy rather than recovering from illness. Fundamentally, she believes that every individual can and does make a difference and that harnessing the energy of many individuals into a unified movement can bring change for healthcare in positive new directions.

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