Readme Magazine Features Lisa Nelson and Janie Appleseed

Lisa Nelson was featured in a magazine called Readme that is published in the Netherlands, so the article was written in Dutch. It's title, "Bijzondere mensen. Bijzondere prestaties", means: Special People. Special Achievements.

This section in Readme features extraordinary people who are making a significant difference for healthcare technology around the world. Nelson, the founder of the US-based nonprofit Janie Appleseed Network, was the focus of the July 2016 edition. The article highlights the achievements of the organization. It also includes some background on Lisa and gives insight into her reasons for starting the organization and her motivations for making Janie Appleseed Network not for profit.

Below is the translation of the Readme article in English:

An "extraordinary achievement". That's how we sometimes describe the work which we do for our clients. We strive for quality and constantly challenge ourselves to perform even better, even when things aren't going well. At the same time we realize that there are people who perform exceptionally on a whole different level. In 2014, Lisa R. Nelson from the USA founded the non-profit network "Janie Appleseed", an initiative that aims to use technology for personal health records by consumers. By stimulating the acceptance and the use of this technology, Janie Appleseed wants to help people improve their lives by using health information and technology. But the organization goes beyond that. Janie Appleseed wants to help patients and caregivers contribute to the development of this new type of personal health information technology.

The first question everyone has, is where the name Janie Appleseed comes from. Lisa: "The name was inspired by the pioneer Johnny Appleseed, who started apple orchards across America in the beginning of the 19th century and in that way contributed to the development of the country. Janie Appleseed does a similar thing with technology for health information. We help with the distribution and the development of health information technology for the 21st century. Our goal is to unite consumers and to improve the American healthcare system while lowering unneeded costs of care, through the use of personal health technology. We also want to create a system which focuses on preventing disease by living a healthy life, instead of treating disease."

Non-profit organization
There are more commercial initiatives for using personal health records in the States. The most known example is perhaps that of Google, which launched Google Health in 2008. This service was canceled in 2011 and eliminated in 2012 because, according to Google, people were reluctant to share data regarding their health and lifestyle with the search engine giant. "It's not just a logical choice, it's instinctual too", says Lisa. "Trusting your entire health history to a commercial venture which may not employ data sharing practices

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you are fully aware of or comfortable with – who wants to do that? I believe offering a solution for personal health records should not be a for-profit endeavor. That's a non-existent solution currently in the States. That's why Janie Appleseed is a non-profit organization."

Fully transparent
Janie Appleseed goes quite far in its quest for independence. For instance, the network will be launching a personal health record, which is being managed as a cooperative. The people who store their health information in it as it were, run the organization. Lisa: "One of the basic principles is the information governance policies concerning data sharing are fully transparent to the participants. If participants choose to share their data for research, quality or other health initiatives, then appropriate extractions will be created. Only the minimum required data will be released and it's guaranteed that this data does not include protected health information that would allow the information recipient to identify individuals within the dataset. Furthermore – and this is where we greatly differ from commercial initiatives – the

revenue derived from delivering the data is shared with the participants who contributed their data.

Good with technology

Lisa has a background in developing and using standards for exchanging healthcare data. She has several HL7 certifications and is currently working on FHIR. She is active in several organizations that develop healthcare standards. "My motivation to start Janie Appleseed was initially a personal one. I became the caregiver and legal guardian for my aging parents. This opened my eyes. We currently have a generation of people who are comfortable with technology, but don't always have the skills they need to get started. This is the generation that is being sandwiched by caregiving to both the younger and older generations. Those two factors – the emerging technology standards and the need to use technological to care more efficiently and effectively for our families – were the starting point for Janie Appleseed. I literally had a dream, to create new technology which would enable people to live differently: stay healthy and better manage their health conditions."

Personal motivations

By themselves, these are clear motivations within the framework of her field, but what was Lisa's personal motivation? "I think that each individual can and must make a difference. By combining the energy of a lot of people, it's possible to bring about change. Moreover, I consider it a personal mission to contribute to a broader understanding of what it means to live a healthy lifestyle. Closer to home: I feel responsible to take care of my family. When my parents needed to be taken care of and, at the same time, I was taking care of school-age children, I nearly had to quit my job. I was used to using technology to work more efficiently and effectively, but the technology I needed to take care of my family simply didn't exist. My sister and I created spreadsheets to record health and financial information for our parents and e-mailed them back and forth to help us keep track of their care. There had to be a better way, I thought."

Discount for risk avoiding behavior

Lisa especially views the stimulation of the demand for personal health records to be a big challenge. According to her, people need such a system; they just don't know it yet. "That's why Janie Appleseed was created, to provide a learning platform and a system which can develop itself organically. Quite a bit like the way a social network grows, actually. Learning new habits, like the use of technology to manage information on health and well-being, is a personal and cultural change. It requires new skills and a new look at life. But product innovation and interoperability are challenges we face at Janie Appleseed." There are countless additional benefits to using a personal health record system. For instance, in the US there are insurers who give people discounts when they avoid risk. Lisa: "When people gather, analyze and use data about their health, they begin to make different choices that lead to a healthier lifestyle. This results in lower healthcare costs that can be given back to people with a personal health record. This is a win-win situation."

Lisa views Janie Appleseed as her life's work. "Someone once told me that there are two important moments in life: the day you are born and the day you realize why you were born. This initiative allows me to use my technical abilities to realize what a personal health record system is and can be. At the same time, I use my business skills to run an organization that creates jobs that are suitable to the information age. But perhaps most importantly: I help people to live healthier and more fulfilled lives through the use of information technology. Janie Appleseed feels like I'm doing what I was born to do. The feeling I get from that is very satisfying."

Inform politicians

Debate what is possible with doctors

Keep my spouse healthy

Foto's: Bron Lisa R. Nelson

Inspire future generations to choose wellness

Take care of Mom and Dad

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