

Patients and people at the heart of health

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“If we really listen to patients, they will tell us what to improve and even how to improve. Let patients be your partner on services, quality improvements, treatment plans, and more.” [Stefanie Weiland and Stephanie Koczela](#) [1]

In the late 1990s, Lithuania had some of the highest death rates due to heart disease in Europe, marked by lack of coordination between primary care and specialists, inefficient systems with staff resources misaligned with need, and resulting poor patient outcomes and low quality indicators. An initiative launched the Eastern Lithuanian Cardiology Programme (ELCP), which set out to transform how cardiology services were delivered by shifting away from the hospital-centric delivery of care and the concentration of care in urban areas. The result was an increase in medication and services where they were most needed and an improvement in patient outcomes as part of an overall reduction in morbidity and premature mortality. Simple measures such as an increased focus on coordination of services, more engagement with the patient and caregiver, and a shift in thinking around improving efficiencies were key to this success.

People centred health services

At May's 69th World Health Assembly, the example of Lithuania was cited a source of evidence and inspiration for the newly adopted [Framework on integrated people-centred health services](#) [2]. As Dr. Hernan Montenegro of WHO noted, *“Addressing the needs of people rather than individual diseases, and improving coordination of care, must be the focus of health services and public health programmes.”* The new framework set out five strategies to create and steward systems in which all people have equal access to quality health services where and when they need them including

1. Empowering and engaging people and communities;
2. Strengthening governance and accountability;

3. Reorienting the model of care;
4. Coordinating services within and across sectors;
5. Creating an enabling environment.

An opportunity for the NCD community

This initiative is not the first of its kind, and many other initiatives and concepts – the work of the World Economic Forum on [Human Centred Health](#) [3], shared decision making in health, health technologies oriented around the individual living with or at risk for disease – have emerged in recognition of the need for this shift. But the WHA adoption of the framework presents a specific opportunity to influence how systems around NCDs will develop, particularly in relation to universal health coverage (UHC) within the SDGs. The NCD community has an opportunity – perhaps a once-in-a generation moment - to address the fragmentation of the health systems and offer joined-up solutions with people at the centre.

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Putting the person at the heart of health

Part of success will require harmonising and realigning systems that on the one hand are organised to address infectious disease, mainly in LMICs, and on the other oriented around ever greater specialisation around NCDs, mostly in HICs. Placing the needs of the *patient* – or rather the *person* - at the heart of the system helps to overcome this polarity, in part because people are not vertical: they present with communicable and noncommunicable health issues, and with dormant and acute conditions. Within NCDs, time and unpredictability are also critical factors: a person living with an NCD often experiences a condition that resists the narrative logic of a beginning, middle and end, so it is important that systems recognise this and allow for lifelong care that may progress or improve over time.

Meaningfully involving people living with NCDs

To make sure that people living with NCDs are informing policies and systems, and ultimately that such systems are designed with people in mind, the NCD Alliance is compiling inputs of people living with NCDs to produce an *Advocacy Agenda of People Living with NCDs* to serve as a compass for the community and to place people at the centre of advocacy efforts to bring about improvements in NCD prevention and control. Listening to people's views on the changes they want to see as well as how they would like to be involved must inform concrete programmes that meaningfully involve people living with NCDs. It is time to borrow the disability movement's mantra “Nothing about us, without us”.

A personal story

I will close with a personal story. Seven years ago I received a call that my stepbrother had been found dead in the houseboat he had been renting in Boston. He had been successfully treated for many years for schizophrenia, and had even graduated law school and had a child, though in recent years he had been going through an especially challenging period, in part due to other health issues, some of which were connected to the side effects of his treatment. When we went to the houseboat to collect some of his belongings, the few possessions told much about his life: a clean kitchen, neat clothes, well-used running shoes, pictures of his son and other beloved family members, a dog whom he adored, but also a letter on the kitchen table denying him service benefits, an unemployment check that underscored his financial challenges, cigarette butts that told the story of the habit he had picked up during a period of institutionalisation 15 years before, multiple medications to manage symptoms and treatment side effects including weight gain and shortness of breath. After toxicology reports came back, it emerged that he had died of a heart attack at the age of 42. What strikes me most when I think back to the houseboat is how *splintered* the various elements of his life seemed, despite his heroic efforts to build a cohesive and meaningful existence. The fragments he had tried to stitch together revealed not just a system that had failed him, but indeed one that could never have met his needs because it didn't understand what he or anyone experiencing chronic illness needed. I believe his death could have been prevented, had the door through which he entered the health system been one that took into account the whole person, not the current structure which has different doors for different diseases and funding sources, none of which connect in any meaningful or sustained manner.

Health systems that begin and end with the individual could save others from what he experienced, for we are all like him – humans with health challenges and strengths, illnesses that interact with one another and treatments that bring relief and sometimes issues of their own. A structure that recognises this could not only save money but also reduce unnecessary suffering and death and provide insight into how to live healthy, productive lives, with or without NCDs.

About the Author

Johanna Ralston ([@johanna_ralston](#) [4]) is outgoing CEO, [World Heart Federation](#) [5] and Vice Chair, NCD Alliance. She has over twenty years of global health and development experience. Prior to becoming CEO of the World Heart Federation, Johanna served as Vice President, Global Strategies at the American Cancer Society (ACS). While working at ACS, Johanna utilised her leadership skills to build up their Global Health department, launching ACS University (a programme aimed at strengthening civil society's role in cancer control in low- and middle-income countries) and the international roll-out of Relay for Life, as well as leading global tobacco and cancer control projects in more than 30 countries. Johanna is an alumna of Harvard and the Harvard Business School Advanced Management Programme, and has studied public health at Harvard and Johns Hopkins Bloomberg School of Public Health.

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- [1] <http://globalhealth.thelancet.com/2014/10/07/time-now-patient-centred-innovation>
- [2] <http://www.who.int/servicedeliverysafety/areas/people-centred-care/en/>
- [3] <https://www.weforum.org/projects/human-centric-health/>
- [4] http://twitter.com/johanna_ralston
- [5] <http://www.world-heart-federation.org>