

Anna Nilsson Vindefjärd - Founder & Secretary General, Research!Sweden



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20.06.2019

Tags: [Sweden](#), [Research](#), [Research!Sweden](#)

Anna Nilsson Vindefjärd of Research!Sweden, explains the critical role of the foundation as a neutral actor in Sweden's healthcare ecosystem, gathering prominent individuals from politics, regulators, academia, patient groups, healthcare and industry who agree on one thing: the need to make medical research and innovation a national priority.

As a donor-funded foundation that collaborates with a variety of different stakeholders in the research and healthcare landscape in Sweden, why did you decide to set up Research!Sweden and what role does it play in the Swedish ecosystem?

During my career, I have held roles in academia, government, and industry. After completing my PhD and postdoc in Medical Innovation, I realized there was a lack of knowledge on how medical innovation works and I wanted to educate decision-makers about the importance of looking at medical research, innovation and healthcare as one system. I began working for the government as Sweden's first Life Science Attaché at the Swedish embassy in Washington D.C. In this position, I became acquainted with the inner workings of politics, which I felt abided by different rules than the research world. As a researcher, your interests lie in seeking new knowledge and spreading it. However, that knowledge and related implications might not always be in line with political ideology. As a result, policies that would enhance research and innovation had the potential to be

disregarded because of political reasons. Of course, this is the way things work in many countries.

Although thoroughly enjoying the position at the Embassy, I thought that it might be more effective to work from an industry-platform, so I moved positions and began working as Director of Research & Innovation Policy at the Swedish Association of the Pharmaceutical Industry (LIF). I ran into another wall because some politicians would have trouble trusting somebody from the industry. I was flabbergasted as I had never been questioned before for being untrustworthy. As I still had a part-time research position at the Karolinska Institutet I could put that hat on and found that then politicians would be much more inclined to listen and discuss serious issues. I realized that in order to gain politicians' trust, I had to speak from a neutral position with no conflicts of interest or ulterior motives. That is my rationale behind Research!Sweden along with the sense of urgency that our politicians needed to understand the life science system in order to make the key decisions needed to keep the system strong. I shared this sense of urgency with a former chief editor of the largest newspaper in Sweden, Hans Bergström, who suggested that Sweden needed an organization similar to Research!America, a foundation created during the Reagan administration to lobby for increased investments in the National Institutes of Health (NIH) and other medical and health research institutions.

In order to establish Research!Sweden as a trusted actor, we made a "dream-list" of 63 highly respected individuals in Swedish society from the political, academic, healthcare and industrial spheres to create a balanced founders list where no single perspective outweighs the others. Moreover, the list had an equal split between male and female representatives. Starting with three Nobel Laureates in medicine and a former prime minister, everyone we asked accepted the offer to be on the list.

The first goal of Research!Sweden was, and still is, to alert politicians of the situation by providing accurate knowledge and insights, along with policy advice. At the beginning of my research career, Sweden was leading in almost all the statistics, such as the number of MDs with PhDs and the number of clinical trials relative to the population, which would inspire the envy of my colleagues from the United States. However, since then, Sweden started slowly losing its rank. The number of clinical trials has decreased, and so has the number of MDs with PhDs. To be fair, the trend was not isolated to Sweden, but, as a Swede, I had a strong desire to curb this worrying trend and protect our highly ranked research and healthcare system.

Through this work aforementioned, how has Research!Sweden positively impacted the conditions for medical research in the country?

Research!Sweden has two overarching goals. The first is to increase government funding for medical research. In that regard, there was a major increase in medical research funding during the Alliance government and I think the work of Research!Sweden helped push the government in this positive direction. The second goal is for the government to devise and implement a life science strategy. During several years, we worked relentlessly for the government to take steps towards such a strategy, which eventually happened. Moreover, they created a position for this purpose, which today is exemplified by the Office of Life Science. This did not happen by itself. The opposition had to push the government, and in one government session at the Riksdag, the opposition party was waving our report in the face of a minister while urging her to create a national life science strategy and the minister had the same report in her hand, saying that they were working on it.

In order to contribute to a strategy, I created a membership organization in 2014 called the “Agenda for Health and Prosperity”, with a limited number of members, well balanced between patient groups, academia, industry, healthcare and unions. Research!Sweden works with the Agenda members on commonly agreed-upon goals and proposals, each member contributing their own knowledge and experience

Each year, we produce reports and concrete policy advice for the government. The idea is for them or their opposition parties to be able to copy and paste our proposals into the current system. If the government ignores proposals that we believe to be key to a better system, then we work with the opposition to push the government. Since we do not have any party affiliation, we are indifferent to which party is in power as long as the government works to strengthen the medical research and innovation system. As an example, this morning, May 27, 2019, we published a debate article in the Dagens Samhälle, the reference newspaper for political matters, where we announced the publication of our new report, signed by all our members. This is difficult for politicians to ignore. As the proposals we put forward are a consensus of different interest groups, reached after long debates and careful consideration, politicians do pay attention. Exactly two weeks after the publication of our report, the Minister for Health and Social Affairs, the Minister for Higher Education and Research and the Minister for Business, Industry and Innovation jointly published an article stating their ambition to make Sweden a leading life science nation with a list of actions which can be found in our report.

The last two governments have been led by the same Prime Minister, Stefan Löfven. In his very first speech he stated that life science was a national priority. We were invited to discuss with the government on an equal playing field about ways to move forward to strengthen Sweden as a life science nation, which was an excellent achievement for the foundation. I was also asked to be on the government's expert board for life science. Today, even though the system is not perfect, there is a collaborative environment in place. One of the most important roles for Research!Sweden to play is to make sure that perspectives are shared in an intelligent and coherent way, and in the end, lead to sounder policies.

Earlier you mentioned worrying trends with regards to research in Sweden. What are the main reasons behind these trends?

Swedish life sciences suffered from a wave of mergers and acquisitions in the 2000s. This resulted in decision-making centres, as well as R&D and manufacturing capabilities, leaving the country.

Going forward, the way for Sweden to stay relevant is to become a research, development and manufacturing hub of advanced biomedicines and medical technologies. The government understands that it is crucial for Sweden to not only be at the forefront of biomedical research but to also have the ability to produce these complicated biological entities. We have seen considerable investments in infrastructure to facilitate this, and we see companies making use of this.

As you mentioned, clinical trials have been gradually decreasing in Sweden for the last decade. How can Sweden curb this trend and position itself as a testbed of innovative ideas?

We are worried about this trend. At the moment, the healthcare system is heavily focused on productivity, resulting in healthcare professionals not being able to participate in trials as much as they would want to.

Digitalizing and making use of healthcare data in a more comprehensive way in addition to building interoperable systems would free up time for doctors and nurses by removing a lot of manual tasks, freeing up their time to conduct trials. In other fields, everything is digitalized, but not in our healthcare system.

Another way to curb this trend is through Sweden's health data. Last year, we published a report focused on the issue of health data with policy proposals. Sweden is sitting on a treasure trove of health data thanks to its long-standing tradition of developing quality registers. Moreover, according to our survey, 95 percent of the Swedish population say that they actively want to share their health data, with the number one reason being to contribute to medical research. Only one percent declined to share their data, and the other four percent were unsure or did not know what it was. Health data is an incredible source of real-world evidence. However, at the moment this data is fragmented and not easily accessible because there are not enough interoperable systems at a national level.

Medical science is entering a golden age of discovery, with innovative therapies including precision medicine and AI-assisted diagnostics becoming more apparent as the way forward. Can Sweden's healthcare system become a front runner in implementing these new therapies?

This is one of the key questions we focused on in our latest report. Sweden has brilliant researchers and clinicians working on the therapies and technologies that are making precision medicine a reality. Like other countries, the main issue Sweden faces is how to implement these breakthrough but expensive methods into our current healthcare infrastructure. We will have to change from a healthcare system focused on managing chronic diseases at a reasonable cost for society to a system that might have to pay for expensive therapies which can potentially cure some chronic diseases, thus saving money in the long run. The government, regions, and companies need to collaborate on designing new payment models and regulations adapted to this healthcare revolution. With Sweden being a relatively small country, it would be smart for Nordic countries to collaborate on this issue. Discussions are already ongoing with our neighbouring friends.

On this issue, Research!Sweden provides a sense of urgency to the government to take heed. Patients cannot wait: if a cure is out there, they want it. In Sweden, we pay high taxes in order to have equal access to the best healthcare and not have to pay extra. This high-level of quality therapies should be implemented into the normal system as standard.

What would be your final message to our international audience, potentially thinking about establishing themselves here in Sweden?

Sweden has excellent researchers, innovators and clinicians, and we are a country used to collaboration. In Sweden, if you need to talk to people, you can reach them.

In the era of AI and precision medicine, Sweden boasts many assets for research and development and is working to make sure that the ethics are in place and that the regulations work. The role of Research!Sweden is to keep questioning the structures today to build the foundation of tomorrow.

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