Stefan James – President, Swedish Society of Cardiology



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Stefan James, president of the Swedish Society of Cardiology and director of research at the Uppsala Clinical Research Centre, outlines the goldmine of healthcare data that is Sweden's quality registries and how he has been using them to conduct randomized control trials. These trials are now in high demand in both the US and the UK, foregrounding Sweden's innovation nation credentials, particularly in the cardiovascular sphere.

What are some of the most interesting trends in the Swedish cardiovascular space?

It is well known that cardiovascular diseases are the number one cause of death globally. They are prominent not only in the western world but also in developing and eastern countries. It will remain the leading cause of death globally, however, oncology is quickly catching up to push cardiovascular from the top spot, especially as we improve the outcomes of cardiovascular diseases.

An important trend is that we have improved outcomes considerably in the last 40 years. The most important factor behind this is that doctors and physicians are now adept at quickly identifying individuals at risk and thus interfering with potential risk factors. For example, lifestyle habits, such as smoking. Smoking in Sweden has decreased considerably, which correlates to a decrease in some cardiovascular diseases like heart attacks.

Another example relates to the obesity epidemic, which Sweden, like the rest of the world, is subject to. Although people are getting fatter, we are keeping up with the poor outcomes of obesity, because we are interfering with the other risk factors. This, coupled with new medication and medical devices we have access to, means better treatment to help these people.

Finally, there has been a dramatic improvement in the ability to cure and treat cardiovascular diseases. There are some important factors for patient outcomes associated with cardiovascular disease is the healthcare system. In Sweden, we have seen incredible investment into the work stations and laboratories in hospitals, like here at Uppsala University, where we can work to the highest of standards and improve the outcomes of cardiovascular operations.

What makes Sweden's healthcare system so unique when it comes to the improvement of patient outcomes?

In Sweden, we have a very strong tradition of improving our healthcare system systematically. This is mainly thanks to our unique personal ID number that every citizen has. This is given to the Swedes the first minute of birth, or straight away to an immigrant, who receives a temporary ID number, which shifts into a permanent one if they stay. They are used in every interaction with society and mean we can keep complete control of the population.

For healthcare, this is paramount for keeping Sweden a front-runner in terms of a quality system, because straight from the government we have access to a massive amount of data, including survival status. Linked to these mandatory registries, there are discharge registration codes, diagnosis codes and prescription codes, just to name a few. Again, all unique to the individual. This information is transferred to the government who then forward it to the National Board of Health and Welfare and ensures we can keep track of the wellbeing of the population very well.

In addition to this, we have a unique feature which are our Quality Registries. Officially, we have 107 of them, co-funded by the government and healthcare providers. These registries are disease or intervention specific. We have the SWEDEHEART registry, which captures all patients in the cardiovascular sphere. This includes all patients who are hospitalised at a cardio-care unit, those who undergo a coronary artery examination or x-ray, any kind of heart or valve operation, or any secondary disease follow up. This is virtually 100 percent captured into this registry, producing an abundance of rich data with multiple variables.

Capturing this data is voluntary for the healthcare providers, doctors and patients to participate, in nature, so not coupled to financial compensation. However, we have been able to make these Registries so efficient and attractive so in reality, no hospital, department or patient is left out.

Do you see a direct correlation between the development of these databases following patients with an improvement in patient outcomes?

Absolutely! These databases are built for quality care assessment. In SWEDEHEART for example, for the past ten years, we have looked at international guidelines about what treatments are recommended for patients for cardiovascular disease. We then rank hospitals throughout the country, based on their performance; to what degree do they adhere to these guidelines of intervention. If hospitals follow these guidelines to the letter, they are ranked higher, as opposed to if they do not. This was very controversial when it started, as these ranking share the hospital names. Nevertheless, this has created a unique situation of awareness of adherence to guidelines. Moreover, if we perform research, we have evidence basis for our decisions, as recommended by the guidelines.

When checking the adherence to those guidelines, we are simultaneously checking what is the effect of the relationship between adhering to guidelines over time and the patient outcomes. From doing this, we have seen dramatic improvements in positive outcomes. Hospitals that have ranked high and are following these guidelines are seeing much better outcomes.

There was a very interesting study conducted in Sweden, published in the British Medical Journal a couple of years ago, where we compared all Swedish patients with all UK patients who had both suffered from a heart attack. Thanks to the registries in the UK, which are also very well created and maintained by the NHS. Interestingly, and as a surprise to our UK colleagues, was that the mortality rate in Sweden compared to the UK was 30 percent lower, in relative terms. We were asked by our colleagues in the UK what was the reasoning behind this. The main factor we identified in another paper we published, is that Sweden has worked consistently on the adherence to treatment guidelines, with a very consistent outcome over the country. If you have a heart attack in Uppsala, Stockholm, Malmo or far up north, you will receive the same level of evidence-based care. This is contrary to in the UK, where there is such a great disparity in treatment based on location.

First of all, our UK colleagues we disappointed that they did not have as good outcomes, especially when they are deemed to have good healthcare coverage. However, this study was used in their

favour. Many doctors went to their healthcare politicians and used this publication as evidence to receive more funding, as they also wanted to follow their patients and patient outcomes in a more efficient and coherent way.

Moreover, the National Institute of Cardiovascular Outcome Research (NICOR) has licensed our technical infrastructure platform, that we have developed here, to be built in the UK to help track patient outcomes. We are planning a lot of collaboration to use this platform in the UK with the aim of developing better outcomes and progressing further in research.

Sweden has built a world-class healthcare system. Nevertheless, what do you see as some of the rooms for improvement?

One of the major strengths in the cardiovascular space is universal accessibility. Everything is paid for by taxation and access to healthcare is very equal and accessible with extremely high quality. However, the financial incentives here are not as strong as our counterparts in Europe. They have much more funding and increased competition between doctors. In Sweden, doctors do not make a lot of money, and you cannot make more money if you see more patients. Although this creates a fair landscape, the only competition is in the quality of healthcare. In Germany, for example, there is more competition to make money for the hospitals and the doctors

On one hand, we have seen a decline in the number of clinical trials in the country. On the other, I have seen the opposite, with a lot of companies coming here because they want to conduct clinical trials in Sweden due to our standards of high quality. It is much less expensive here, as maybe compared to in the US. Most companies now know that if they enrol in Sweden, the quality will be high with relatively low risk. In addition to industry orchestrated trials, there is a huge number of trials that are academically independent and are not counted in many statistics. Thus, figures of declining clinical trials in the country are not as bad as they sound, and there are a lot more trials being performed that are financially independent from the industry and are just as important.

What are some of the advantages of conducting clinical trials in Sweden?

Within our Quality Registries, we have developed systems to randomize patients upfront, called Randomized Control Trials. This enables the patient to be enrolled in a trial to compare outcomes of different therapies, medications or devices. Patients are asked to participate, and then they are randomly chosen to take a certain medicine for their ailment. This is the only way to statistically

identify a difference between therapies as opposed to letting the doctor choose. This is a unique way of conducting trials.

In this regard, we have seen an influx of companies wanting to perform their trials in Sweden, especially since these randomized trials are impossible to be executed in the US. The FDA, for example, have noticed this unique engineering of data, and they have invited many of us from the Uppsala Clinical Research Centre (UCR) to consult and teach companies how to replicate our system to conduct trials more effectively and less expensively.

Another example of Sweden exporting its efficient model abroad is through a trial we are conducting in heart failure. Although a common disease, it is not well known and thus a real healthcare issue. This trial is being conducted in Sweden, however, the National Institute of Health in Washington asked us to apply for a grant to run part of this study in the US. Although only ten percent of the patients are from the States, they have invested USD 10 million in this trial to learn from our way of conducting trials.

Moreover, the FDA has referred companies who want to do clinical trials but do not know how to do them efficiently to the UCR to run their trials here. These clinical trials began in the cardiovascular space, but have since expanded to strokes, surgical procedures and diabetic care, in addition to further afield in other therapeutic areas. This is really a fantastic achievement for the country.

As president of the Society of Cardiology, do you have any specific objectives during your tenure?

The most important part of the Swedish Society of Cardiology is to engage with the Swedish Medical Association, which is independent of companies and more of a union, to ensure the Swedish cardiologists are educated to the highest of standards. We provide a lot of access to courses and congresses in addition to supporting research to help in this regard.

It is particularly important for a small country like Sweden to collaborate. Although research is pretty competitive, with universities and hospitals competing for funding and fame, we need to work together. It is important to compete, but the society strives to ensure collaboration, and continue fostering interactions between hospitals and universities to create common incentives and join forces. Otherwise, in such a small country, we will be lost.

Any final message to share with our international audience?

I want to repeat that the opportunities that we have in Sweden are unique. With our organised system and society, we have a uniformed way of delivering healthcare. I am proud of the public healthcare system, and I am proud to not make as much money as my colleagues are as individuals in other countries such as Germany or the US in order to contribute to a better society. We have fewer social inequalities and we can all contribute to that. Sweden should be proud that we have equal access to healthcare and we are all a key part in continuing this equality.

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