

## **Bottom-up building approach and cooperation with government – the SwedeHeart Registry**

Jang-Whan Bae MD, PhD

Department of Internal Medicine

College of Medicine, Chungbuk National University, Cheongju, Chungbuk, Korea

Currently, Swedish government operates 96 nationwide, certified registries (total 108 registries), and uses 35 Million Euros to maintain those registries. Those registries include the SwedeHeart Registry, Hip joint replacement registry, and even cataract operation registry. The SwedeHeart Registry composed of Acute Coronary Care (RIKS-HIA) registry, Angiography & PCI (SCAAR) registry, Heart surgery registry, Secondary prevention (SEPHIA) registry, Catheter-based valve-intervention registry, and Cardiogenetic (Arbetsgurpp) registry. The SwedeHeart registry is operated by Uppsala Clinical Trial Organization (UCRO). The initiation of the SwedeHeart registry was not government driven, but from some CCU doctors' questioning. "Do our ACS patients who treated in our CCU well after discharge?". Prof. Lars Wallentin started to make registry team nearby Uppsala Hospital and they made RISK-HIA registry. They have made RISK-HIA with strong intention of bottom-up procedure on the devotions of healthcare providers (Doctors and Nurses in hospital and doctors in community clinics). It started with just paper registry (not computerization), maintained with small grants of HCP, and company sponsored grants later on. From 1990, the cardiovascular disease, especially ischemic heart disease was the number 1 killer in Sweden, the Swedish government needed strong statistical fact sheet for ACS, even though they already had very good national disease statistics in the Swedish National Statistics to improve outcome of the Swedish ACS patients. Finally, the government asked some help to the Swedish society of cardiology and UCR. The Swedish government started funding for the SwedeHeart Registry to get the quality of data. Now, all hospitals which have enough human resources, (facilities for each segments of CV diseases (e.g. heart surgery, CAG or PCI, ACS managements etc.) participate all kinds of the SwedeHeart registry. 80,000 patients are enrolling in the SwedeHeart registry. RIKS-HIA includes 20000 AMI, 10000UA, 25000 other causes of symptoms, SCAAR includes 40000 CAG/PCI, the heart surgery registry includes 7000 heart surgeries. Data input starts with the Swedish personal identification number, and all kinds of epidemiological data would be drawn from the Statistics Sweden (SCB), and the SwedeHeart registry connected with multiple registries at the National Board of Health and Welfare, the Swedish Social Insurance Agency, and other National Quality Registries. The SwedeHeart registry publishes annual report annually, it

shows the important quality measures and clinical outcomes including morality of acute myocardial infarction in the level of nation, communities, and each hospitals. The Swedish government accepts the regional or inter-hospital differences of CV mortality rate, rate of important medicinal use for AMI, the government never does punishment or disincentive system for the low grade hospital. As the central or local governmental operating health care system of Sweden, the Swedish government refers the data of the SwedeHeart, and makes funds or administrative strategies to help low grade hospitals.

To make good national registry of CV disease, we need as follows; the devotion of health care provider, the governmental fund in long period, active response of government to improve quality of care referring data of the registry. Punishment or unreasonable incentive/disincentive system should not be used. It may make data falsification or fabrication of health care providers or institutions.