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Standardization of patient registry: Importance of patient registry for evidence based public healthHiroshi Mizushima¹, Yasutaka Sugamori¹ and Yoko Sato²¹National Institute of Public Health, Japan²National Defense Medical College, Japan

A new legal structure for rare disease (nambyo) has been established in Japan in 2015, after 42 years of measures of nambyo. We have been accumulating registry for nambyo from 2003, however, as it was based on paper registration, quality was not enough. We made a prototype system for online registry used for nambyo reimbursement application. We first categorized all disease, and made standard data sets. Our new registry system will be based under ISO13606 which is a medical international standard. Authorized doctors can put in data on Line by the new system, which has data cleaning filter for accurate data entry. Patients will be supported their medical expense by authorization by this system, so the registry will be efficient. We also made Offline registry system, in case of lacking online access due to security at hospitals. As this system for nambyo was also used for pediatric rare disease registry, it was the good example for broad range of diseases. We were asked to make a guideline for Patient registries as a government funded project in 2016. We compared PARENT which is a European project and AHRQ which is an American guideline for patient registries. There is currently no international guideline or standard for patient registry, however, to perform patient research or integrate worldwide information, which is important in the field of rare disease. We are also trying to integrate patient reported outcomes data using patient portals. It is very important to get patient database for evidence based public health and precision public health.

Biography

Hiroshi Mizushima has his expertise in medical informatics, computer science, public health informatics, molecular biology, etc. He has graduated from University of Tokyo, Faculty of Pharmaceutical Science in 1983 and obtained his PhD in 1988 at University of Tokyo. He has established Cancer Information Service and Cancer Information Network at National Cancer Center and became Professor of Medical Omics Informatics at Tokyo Medical and Dental University in 2009. He moved to National Institute of Public Health (NIPH) in 2011 and became Director of Center for Public Health Informatics at NIPH in 2017. He is currently the President of Japan IT-Healthcare Association and others.

hmizushi@niph.go.jp