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CASE 7

Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology

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“If we don’t lobby for ourselves, we are going to get left in the dust.” Katja Borodulin and her colleagues at the National Institute for Health and Welfare in Helsinki, Finland were responsible for the National FinHealth Study. The national, population-based survey is administered every five years to monitor population health in Finland (National Institute for Health and Welfare, 2018a). The FinHealth survey generates a large volume of high-quality data on health status and health status trends but collecting the data is expensive. National initiatives to reform health services could lead to a decrease in the FinHealth Study budget. The Ministry of Social Affairs and Health funds the National Institute in addition to financing and managing Finnish health services. Amid reforms to expand access to health services in underserved areas, the Ministry is looking for ways to decrease overall expenses. The prospect of replacing the FinHealth survey with less expensive data sources, such as disease registries, would be one approach to lowering costs. A new Director General was elected at the Institute in the fall of 2018, which has made the situation more precarious. The national health care reform could result in a smaller budget for the FinHealth Study, and this would negatively impact population health surveillance in Finland. The Finnish experience has been influential in the global evolution of population health surveys; therefore, Finland’s reputation as a global leader in population health surveillance is also under threat. The FinHealth team was looking for a way to convey the value of population health surveys to those who did not appreciate the quality of these kinds of data. They had to show that alternative sources of population health data would compromise population health surveillance efforts and could, therefore, compromise population health.

BACKGROUND

The National Institute for Health and Welfare

The National Institute for Health and Welfare operates under the Ministry of Social Affairs and Health, but is largely independent in carrying out its role. The Institute’s responsibility is to serve the Ministry, the government, local and provincial decision makers, the research community, and the general public (National Institute for Health and Welfare, 2017a). The Institute conducts research to support developments in health and social welfare service delivery (National Institute for Health and Welfare, 2018b), with the goal of monitoring and promoting the health and welfare of the Finnish population (National Institute for Health and Welfare, 2017a). Recognized internationally for the quality of its work, the Institute produces a large number of high-quality scientific publications each year (National Institute for Health and Welfare, 2017a). The Institute formed in 2009 when two major governmental organizations, the Public Health Institute and the National Research and Development Centre for Welfare and Health, merged to form a new, expert research agency (National Institute for Health and Welfare, 2017b). The original organizations were formed in 1982 and 1992, respectively; however, their predecessor—The National Board of Health—dates back to 1811 (National Institute for Health

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and Welfare, 2017b). The longstanding presence of government institutions designed to promote health and welfare through research has been integral to Finland's remarkable history of population surveillance.

History of Population Surveillance in Finland

The 1930s marked the beginning of a coronary artery disease (CAD) epidemic in the United States that would later manifest in Western European countries (Jousilahti et al., 2016). In the 1950s, Finland saw an increase in CAD mortality, attributed largely to higher incomes and associated changes in diet and lifestyle (Jousilahti et al., 2016). In the 1960s, Finland had the highest rate of cardiovascular disease mortality worldwide (Jousilahti et al., 2016). Large epidemiological studies such as the Seven Countries Study and the Framingham Heart Study, which were conducted on populations outside Finland, had begun to identify behavioural and dietary risk factors for heart disease. Numerous observational studies followed to further support the causal mechanism of such lifestyle factors. Public outcry prompted urgent action to reduce Finland's burden of cardiovascular disease mortality (Puska, 2002). In 1972, the North Karelia Project became Finland's first collaborative, multipronged, community-based intervention designed to decrease the prevalence of risk factors for cardiovascular disease, with the ultimate objective of reducing cardiovascular disease mortality in Finland (Puska, 2002).

The Finnish Minister of Health appointed Pekka Puska, a young physician with a master's degree in social science, to lead The North Karelia Project. Pekka believed that the link between lifestyle factors and CAD risk was clear, and that systems-level changes would be necessary to improve health status (Buettner, 2015). The project prompted widespread lifestyle changes, encouraging citizens to decrease smoking, decrease sodium and saturated fat intake, and increase vegetable consumption (Borodulin et al., 2014). However, the approach also emphasized improvements to the physical and social environments. Pekka lobbied food producers to replace animal fat with vegetable-based products and encouraged farms to freeze native berries to increase fruit consumption throughout the year (Buettner, 2015). Pekka also engaged community members, appointed community ambassadors, and organized cooking classes that taught healthful modifications of traditional dishes (Buettner, 2015). Pekka later served as the Director General of the Public Health Institute, now the National Institute for Health and Welfare, from 2003 to 2013 (Puska, 2013). Before this, he also served as the Director of the Department of Noncommunicable Disease Prevention and Health Promotion at the World Health Organization (Puska, 2013).

The North Karelia Project produced highly favourable results in the Finnish population leading to decreased total serum cholesterol levels, decreased systolic and diastolic blood pressure levels, decreased smoking rates and, ultimately, reduced rates of CAD (Borodulin et al., 2014). From the early 1970s until 2012, CAD decreased by a remarkable 82% in working-age men and by 84% in working-age women (Jousilahti et al., 2016). In the past 10 years, approximately two-thirds of the CAD mortality reduction in Finland has been explained by a reduction in three main risk factors: smoking, elevated systolic blood pressure, and elevated serum cholesterol (Exhibit 1, Jousilahti et al., 2016).

The evaluation of the project's impact was achieved through population-based health monitoring. An important component of the project was the administration of risk factor surveys every five years to allow for continued health surveillance (Jousilahti et al., 2016). Researchers at the Institute have gradually expanded the survey yet have retained many aspects of the original study design to permit comparisons over time. In 2017, past surveillance and monitoring efforts were consolidated and rebranded as the FinHealth 2017 Study.

CURRENT SURVEILLANCE EFFORTS AND LOOMING THREATS

Population-based Health Surveys

The FinHealth 2017 Study is a national, population-based survey designed to monitor population health, assess changes in health, and project future health trends (Koponen et al., 2018). The researchers selected a random sample of participants using a multistage clustered sampling design based on the national population registry. Participants were invited to complete a mail-in questionnaire and asked to attend a physical health examination (National Institute for Health and Welfare, 2018a). Information about an individual's health, health behaviours, and functional capabilities were collected to provide a comprehensive overview of health status (Koponen et al., 2018). Survey sections included demographic information such as age, education, income and marital status, general health status, functioning and welfare, exercise, smoking, nutrition, height, weight, and sleep habits. During the health examination, highly trained nurses took physical measurements such as height, weight, and blood pressure using standardized protocols. Teams of nurses travelled across Finland to a total of 50 different locations to ensure that the data are representative of the entire nation (National Institute for Health and Welfare, 2018a). To reduce seasonal variation, the teams strove to complete all assessments within a short time frame at the same time of year in each survey cycle. A subset of participants was invited to complete a second questionnaire. The second questionnaire obtained more detailed information on illnesses, quality of life, working life, assistance requirements, social relationships, mood, reproductive health, and physician-issued recommendations regarding lifestyle changes.

Researchers in Finland have been collecting data on key health indicators using national surveys and administrative registries for more than 50 years (Kilpeläinen et al., 2016). The cross-sectional surveys allow for quantifying the prevalence of risk factors and identifying targets for public health action. Comparing the results over survey cycles allows for the monitoring of trends using time series analyses. Follow-up with participants using special registries permits the creation of cohorts that can be further studied over time. The findings of the health examinations provide invaluable health information to support targeted health promotion.

Dr. Seppo Koskinen leads the FinHealth 2017 Study. Seppo is a research professor who has worked in the Public Health Solutions Department at the National Institute for Health and Welfare for more than 20 years. Seppo's background and training include medical science, epidemiology, and political science. Before joining the Institute, Seppo worked as a researcher with the Academy of Finland/University of Helsinki, studying mortality and health inequalities. Seppo was keen to see how the upcoming health care reform might reduce inequities in accessing health care. However, he was also concerned that the reform would force the Institute to alter its surveillance methodology, which would diminish the quality of population health surveillance.

Population health surveillance in Finland has inspired the implementation of national, comprehensive health surveys in other countries. For example, Statistics Canada, Health Canada, and The Public Health Agency of Canada developed the Canadian Health Measures Survey to use direct physical measurements to collect robust, objective, and comprehensive data on the health of Canadians. Statistics Canada cited the experiences of countries such as Finland, which have a history of deriving important findings from direct health measures, as influential in providing the rationale for implementing such a survey in Canada. The goal of introducing the Canadian Health Measures Survey was to address knowledge gaps in the health status of Canadians that could not be addressed by questionnaires or interviews alone (Tremblay et al., 2010). Finland's history of health surveillance has also inspired the

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development of the European Health Examination Survey, which aims to standardize national health examination surveys in European countries and to enhance comparability of population health findings (Kuulasmaa & Tolonen, 2016).

Some health officials within the Ministry believe that administrative data and local patient registries would provide adequate substitutes for population health surveillance. Indeed, many patient registries began as cohort studies that grew out of earlier versions of FinHealth surveys. Administrative data reflect utilization of health services, such as physician visits and hospitalizations, provided by the Ministry. Administrative data are fairly comprehensive reflections of health service utilization and contain a unique personal identification code that allows for data linkage across databases and across registries (Kilpeläinen et al., 2015). Some registries also contain information on health service utilization. Linked administrative databases and registries can be used to estimate the prevalence of some conditions and to identify causes of mortality (Kilpeläinen et al., 2015). Pertinent health data found in databases and registries can be analyzed at a minimal cost. However, information on health behaviours, individual perceptions about health, and social determinants of health are lacking (Kilpeläinen et al., 2015). Administrative databases and registries only capture information on people seeking services, while data on apparently healthy or symptom-free people are lacking. Therefore, administrative databases and registries alone do not provide a comprehensive picture of health status at the individual and population level. For example, prevalence estimates from these data may not reflect true population prevalence.

Health Care Reform in Finland

Despite Finland's universal health care system, many people in Finland still face difficulties accessing services. Access is poorest among people residing in smaller municipalities where the Ministry faces service delivery challenges. As a result, the Ministry plans to launch a national regional government, health and social services reform. In 2020, the Ministry will centralize service delivery, shifting responsibility for service provision from local municipalities to 18 newly formed autonomous counties (Ministry of Social Affairs and Health, 2018a). The goals of the reform are to promote client-centred care along with vertical and horizontal integration of social welfare and health care services. The larger, more financially viable administrative bodies will organize and provide services with the aim of eliminating inequities previously faced by smaller municipalities (National Institute for Health and Welfare, 2018b). The reform will be the largest national-level restructuring of health service delivery in Finnish history and, consequently, has become a highly publicized national priority. The Institute has a key role to play in the coming reform and will be responsible for providing expert assistance through steering groups and anticipatory evaluation (National Institute for Health and Welfare, 2017a).

ADVOCATING FOR SURVEILLANCE

An Uncertain Future

Seppo sat with his colleagues Katja, Päivikki, and Kimmo discussing the health care reform. Katja was a research manager and senior researcher in the Health Monitoring Unit at the Institute. Passionate about chronic disease prevention and physical activity, Katja did not want to see cuts to the FinHealth Study budget. Päivikki Koponen was also a research manager in the Health Monitoring Unit, with a background in nursing and public health and an interest in migrant and refugee health. Kimmo Parhiala was the senior planning officer at the Institute, responsible for leading anticipatory evaluation of the reform's impact. The team was discussing how the reform would shape the Institute's research priorities in 2019. With national attention on health care reform, the ever-shrinking budgets for disease prevention and health promotion would make population-based studies a lesser priority. The surveillance and monitoring efforts of the FinHealth Study team would be compromised.

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“Right now, our futures are really quite uncertain,” Päivikki said to her colleagues “with the new Director General facing pressure from the Ministry to reduce spending.”

The Director General, who was elected in the fall of 2018, is responsible for all decisions at the Institute. Although the Institute operates independently, it is mandated to support the Ministry of Social Affairs and Health.

“I wonder if the new Director General will be able to justify the cost of retaining health surveys” Katja added. “The former Director General did believe that research is important and that the high-quality data we collect is valuable; however, he was also quoted criticizing population health surveys that have a participation rate of ‘only’ 60%.”

As it was still early in the new Director General’s term, the team was uncertain if he too would feel that participation rates of 60% called into question the value of population health surveys. The team reflected on the background and training of the new Director General, which included training in medical science and experience working at various levels of government (Ministry of Social Affairs and Health, 2018b). The team was anxious to discover if the new Director General would view population-based studies as an important asset both for research and policy decisions. They wondered if he appreciated survey design, data quality, and the cost-effectiveness of prevention.

“It is true that our surveys are expensive; however, the survey data are not only used for surveillance and monitoring, these surveys are also a rich epidemiological data source. I’m not sure that health survey critics are aware of how much our data are used. Within the Institute, in collaboration with local universities, and in international collaborations, our data have revealed quite important findings” commented Päivikki.

Päivikki also expressed concerns about the alternatives to the FinHealth survey. “There are many challenges associated with using administrative data registries such as primary care registries for population health surveillance. There are many different service providers and many different information systems capturing data. Inconsistencies in these information systems, and a lack of integration across different systems make data sharing challenging. Another concern is that not all service providers are collecting data regarding patient characteristics or service use, and others may be collecting the data but not sharing it.”

Katja echoed Päivikki’s concerns about the fragmented systems and shared additional concerns about incomplete data. “Administrative patient registries only capture the use of health care services—they do not signify the need for services. This information is important in planning health promotion and prevention initiatives.”

Seppo examined the figures that Katja and Päivikki had prepared for the meeting. The figures compared discrepancies in prevalence estimates from registry data only with estimates derived from registries and surveys used together (Exhibit 2). Presenting these figures to Ministry officials would illustrate the gaps associated with registry data.

Katja continued. “Patient registries such as primary care registries do not currently cover the private sector. The majority of the working-age population who seek occupational health care from their employer may not be captured by such registries.”

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Seppo listened carefully to Katja and Päivikki. Both had a great deal of experience in the design and administration of population health surveys. Both understood well how study design and data collection processes impacted data reliability and representativeness. Seppo knew that Kimmo held a decidedly different opinion. Confident that the reform would improve equitable access to health care services, Kimmo was less concerned about the source of health surveillance data and more concerned about patient access to necessary services.

“The most problematic aspect of Finland’s current health care system are issues related to access” stated Kimmo. “Those employed are better off, but those not working face challenges with access and high wait times. Smaller municipalities also currently have fewer services and service providers. The reform has the potential to improve access. The reform should also improve the quality of care. We see stark regional differences across municipalities, but we will see some standardization across counties once the reform is in effect. Population health is important, of course, but there is more to the health system.”

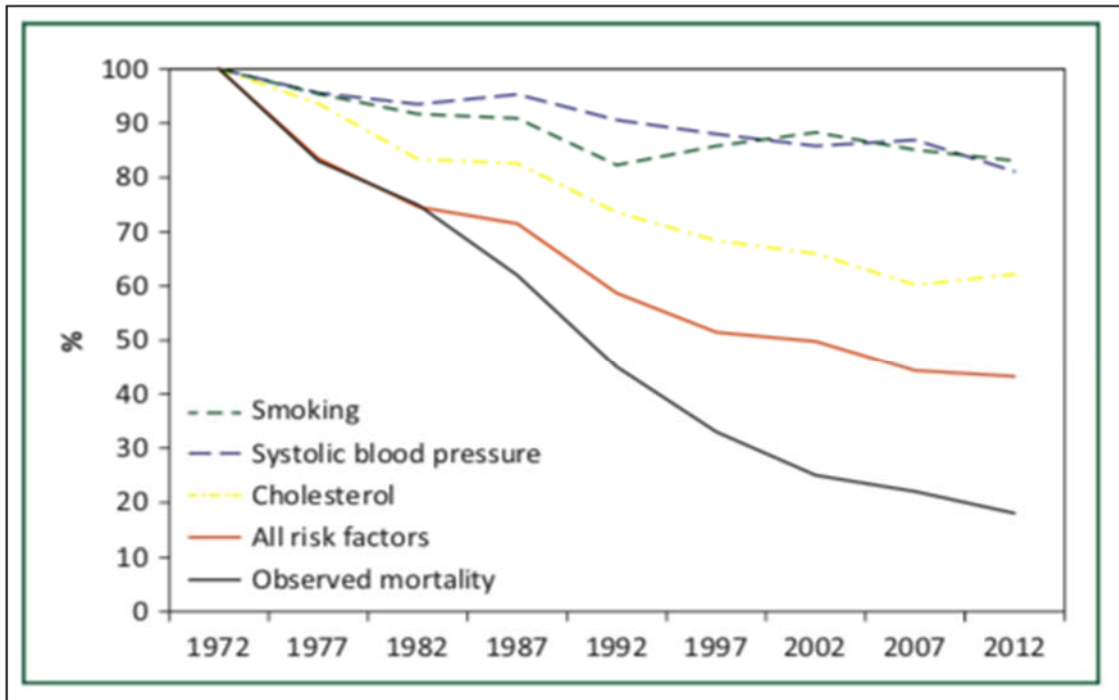
Päivikki was quick to respond. “That’s true, there are many aspects to the health system, but with the recent prioritization of the health care reform, health officials are considering *only* health care services. We have to do more than take care of the patients once they come in for service—there is so much more we can do *before* that.”

CONCLUSION

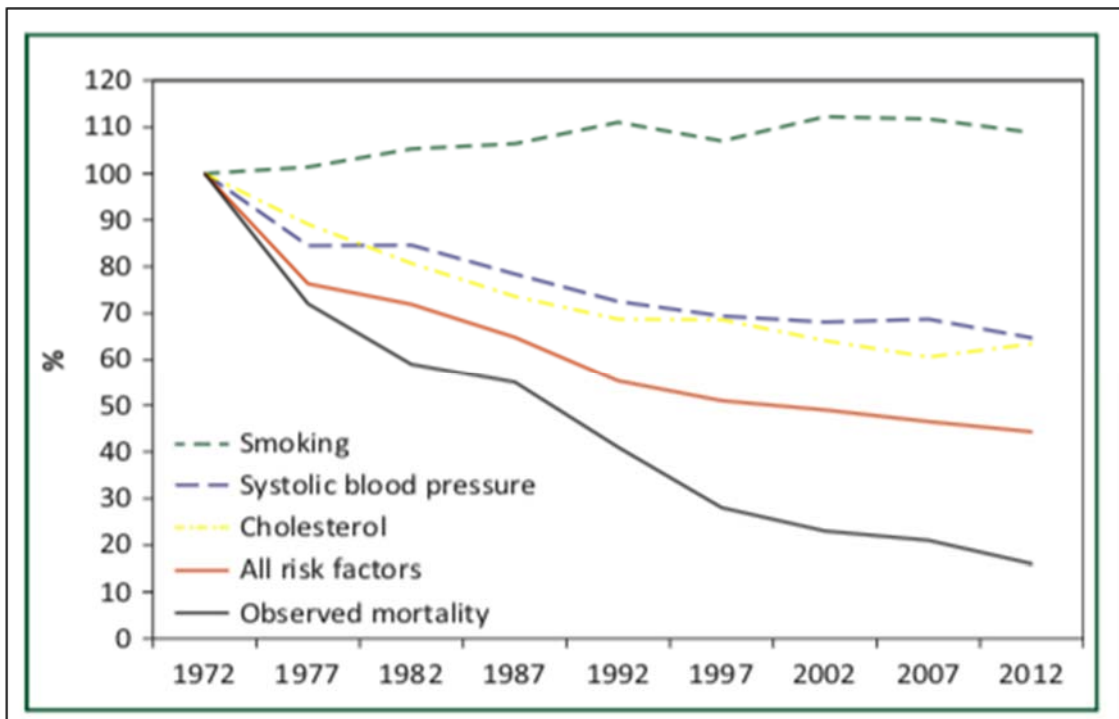
Seppo was quiet. Concerned by the lack of consensus regarding priorities for population health, he reflected on both perspectives. On one side, those responsible for leading and guiding the reform were motivated by improved access to health care services. On the other side, those responsible for population health surveillance resisted changes to historically strong surveillance efforts, motivated by a desire to maintain high quality surveillance data. As the head of the FinHealth 2017 Study, Seppo wondered what he could do to advocate for population health surveys. How could he convey the value of population health surveys to leadership within the Institute and at the Ministry of Social Affairs and Health? How could he illustrate that the long-term, downstream repercussions of compromised surveillance would not be cost saving at all? Ultimately, population surveys had revealed the significant decline in CAD mortality and decrease in risk behaviours after the North Karelia project was implemented. More recently, FinHealth survey data supported research projects on a range of topics including cardiovascular diseases, asthma and allergies, alcohol use, socioeconomic factors, and genetic epidemiology (National Institute for Health and Welfare, 2018c). The push for reforms had been driven by an aging population, inadequate access to care, inefficiencies in service delivery, long wait times, and budget constraints. Without adequate surveillance, how would the Ministry know whether the reforms were achieving intended outcomes?

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**EXHIBIT 1
Predicted and Observed Reduction in Coronary Artery Disease Mortality
from 1972 until 2012 in Eastern Finland**



Men 35 to 64 years of age



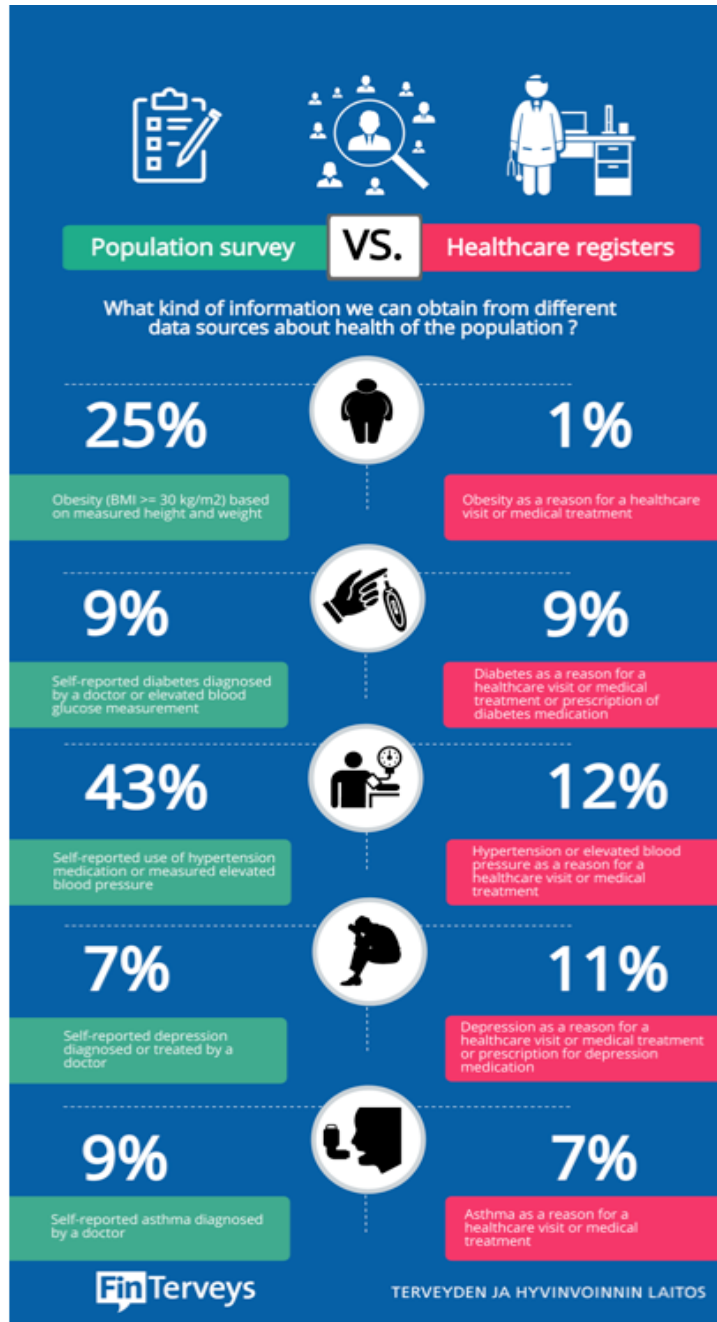
Women 35 to 64 years of age.

Source: Jousilahti et. al., 2016. Permission to reproduce granted by Copyright Clearance Center.

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EXHIBIT 2

Discrepancies in Prevalence of Health States Detected Using Alternative Data Sources



Note: BMI is body mass index

Source: Koponen et al. 2018. Infographic was created by Hanna Tolonen, National Institute for Health and Welfare (THL), Finland and permission to reproduce granted based on the Creative Commons by-NC licence.

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INSTRUCTOR GUIDANCE

Population Health Surveillance in Finland: Threats to Historically Dependable Surveillance Methodology

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BACKGROUND

The case outlines the challenges that the National Institute for Health and Welfare in Helsinki, Finland is facing in light of an ongoing national health care reform. The health care reform has taken precedence over other research activities, and the Institute is anticipating changes to population health surveillance methods. The Institute elected a new Director General in the fall of 2018 who will influence decisions about which population surveillance data collection methods are used. The Health Monitoring Unit at the Institute fears that the Director General will decide that all surveillance data will be collected using administrative patient registries with the consequent elimination of population health surveys. The team responsible for the 2017 National FinHealth population health survey must determine how they can advocate for the continued use of survey data in population health surveillance.

OBJECTIVES

1. Compare alternative methods for collecting population health data using knowledge of study designs to analyze strengths and inherent sources of bias for each method.
2. Discuss the importance of, but challenges associated with, evidence-informed decision making in public health and practice making decisions with limited or insufficient evidence.
3. Recognize foundational epidemiological concepts such as risk factors, prevalence, simple random sampling, surveillance, study designs, secondary data, and levels of prevention.
4. Illustrate how descriptive epidemiology can be used to quantify population disease burden and support surveillance.

DISCUSSION QUESTIONS

1. Explain the stages of the epidemiological research cycle.
2. What is the design of the FinHealth 2017 Study? What are the strengths and weaknesses of different observational study designs?
3. What are the advantages and disadvantages associated with alternative sources of population health data?

KEYWORDS

Cross-sectional study; epidemiology; evidence-informed decision-making; population health; prevalence; registry data; surveillance; survey data