

**Evaluating the Structure and Performance of Nordic Public Health Surveillance Systems:  
A Literature Review**

by

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University of Pittsburgh, 2023

## **Abstract**

This narrative literature review assesses the current practices and outcomes of public health surveillance systems in Nordic countries. In the United States, efforts to reorganize, modernize, and improve public health surveillance are ongoing in response to multiple public health emergencies. Therefore, it is important to examine and compare the practices of other countries and systems, particularly ones that have better health outcomes and different approaches to surveillance like in Nordic countries. This review presents several barriers to public health surveillance improvements in the US, such as old technological systems for reporting and decentralized data authority; this review further examines potential barriers in Nordic systems and how they were overcome. This study found that the Nordic countries rely primarily on public health registries for nearly all of their surveillance activities. These registries rely on personal identification numbers assigned to all residents, which link all their health and demographic data to national systems. Through careful data anonymization practices, privacy concerns have largely been eliminated and these systems are widely supported by the population. Nordic countries have also focused on modernizing their tech systems, automating reporting, and standardizing data collection. The literature shows that these practices create a system with large amounts of complete data that is quickly available to researchers and decision makers. Continuing to improve surveillance systems is crucial to public health practice and research because when epidemiologists and decision-makers get data faster, lives are saved.

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## **Preface**

I'm extremely grateful to my essay readers Dana Pitts, Dr. Lindsay Sabik, and particularly my advisor Dr. Tina Costacou for helping guide me along this process. I would also like to thank Dr. Nancy Glynn for her much-needed encouragement and motivation. Finally, I'd like to acknowledge Jessica Alexander for her excellent editing skills.

## **1.0 Introduction**

Public health practice is increasingly reliant on rapid collection and dissemination of health data. Conducting effective disease surveillance has been a core public health principle since the inception of population health. Surveillance is described by the CDC as the, “ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health” (Chiolero & Buckeridge, 2020). Surveillance systems are the policies, processes, and mechanisms through which crucial public health data is recorded and disseminated. Surveillance is used to monitor the incidence and prevalence of disease or health concern, generate hypotheses which could be subsequently used in designing research studies, evaluate the impact of public health interventions, and more. Data produced are invaluable to decision-makers as they allow them to assess the need to act on a public health issue as well as to evaluate the effectiveness of an existing program. In the post-pandemic age, private industry is also reliant on accurate and timely infectious disease data to evaluate risk to persons and property. Surveillance is therefore the foundation of an active and effective public health system for it is necessary to the work of all levels of public health including government, non-profits, and researchers.

Surveillance systems are the focus of this review. They are the fundamental infrastructure that public health systems rely upon and require continual improvement and iteration to meet the challenges of the modern world. In the US, the nature of the decentralized public health system, where different authorities and responsibilities are distributed among federal, state, and local jurisdictions, creates a unique environment for public health surveillance. This review identifies a

multitude of barriers that inhibit the optimal implementation of surveillance systems in the US and discusses how these limitations have impacted recent public health crises.

This review further delves into public health surveillance systems in a completely different public health context: the Nordic countries. With significantly better health outcomes and a structurally different healthcare environment, differences in surveillance systems and practices can shed light on areas of improvement in the US. While there are fundamental differences between Nordic societies and the US, public health is a science where best practices can be studied and applied in many different contexts. This work seeks to review the academic literature on Nordic public health surveillance systems to explore the types of surveillance systems primarily used, how they function, the strengths and weaknesses of these systems, how modernized they are, if they encountered similar barriers as those the US faces and how they were overcome.

### **1.1 Barriers to Effective Surveillance in the US**

The barriers to effective surveillance in US public health have been apparent to experts for many years. While surveillance barriers are universal, the American decentralized, fragmented public health system presents unique challenges. Panhuis et al. identified 20 “unique real or potential barriers to data sharing in public health and classified these in a taxonomy of six categories: technical, motivational, economic, political, legal, and ethical barriers (van Panhuis et al., 2014).” The motivational category describes a general apathy towards improving systems and considering the substantial investments in public health surveillance recently (particularly the CDC’s Data Modernization Initiative), motivational barriers have been eliminated in the US. Detailing all of the potential barriers is outside of the scope of this paper but in brief, the most

immediate barriers are the decentralized public health system, antiquated technology, lack of funding and investment, and the issue of data authority (van Panhuis et al., 2014).

The US public health system reflects the federalized government structure of the US, where localities and states often exert greater authority than the federal government. State, local, tribal, and territorial health departments are independent of each other and of the central public health authority at the CDC. There are other federalized public health systems in Australia, Canada, and Germany, but these countries had significantly better outcomes during the COVID-19 pandemic. Their responses prioritized coordinated testing programs and creating consensus on quarantine practices between states which, along with different social welfare and healthcare systems, led to improved outcomes (Rozell & Wilcox, 2020). While the decentralized system has advantages like tailoring policy to localities, in general it slows decision making and data collection. Decentralized data collection is hampered by different systems, data standards, and different funding streams. If the data reporting systems differ, delays in data merging and analysis occur. If the data are not standardized, costly time and effort must be spent on corrections, which would assure that merging data from different sources is valid.

A key to effective surveillance is the central collection of all national health data (Hamburg et al., 2022). Health data is all the information related to an individual's health that could influence outcomes, quality of life, and other determinants of health. Health data is used by public health agencies to monitor and respond to public health concerns. The flow of health data starts with individual healthcare providers and laboratories, who send data to insurers and state and local health agencies. CDC is positioned as the pre-eminent public health agency in the US, to which all other levels of public health look to for best practices, best data, and guidance. States are largely responsible for the ground level collection and surveillance of disease and then share what they

choose with the federal government. Restrictions on what data the CDC is legally able to access creates a barrier to coordinated disease surveillance. States choose not to share data with the CDC because of privacy concerns, some outdated laws, and workload constraints (Antonios, Chatterjee, Gee, Kravitz, & Senese, 2021).

The CDC lacks the authority to compel states or jurisdictions to share health data except through temporary declarations of public health emergencies. During the critical early months of the COVID-19 pandemic, the CDC was forced to individually negotiate data sharing agreements with each partner, which took months and delayed crucial data from reaching the CDC in time. Legislation is pending that would address this barrier, but it is not guaranteed to pass. If the US is to learn from the mistakes made in efforts to address the COVID-19 pandemic, eliminating this barrier is crucial to creating a more interconnected, modern public health system.

The next barrier to effective surveillance is the antiquated technological systems for data collection and sharing. Currently, each state has the autonomy to use the data collection system of its choice. Different systems, often old and outdated, make data sharing between states and with the federal government a multi-step and time-consuming process (Feehan, Kahn, Vuppala, & Yau, 2022). The fundamental issue is that of interoperability. These surveillance systems do not share information seamlessly and automatically and do not use common data standards. Cases are classified in different terms, demographic data are inconsistent, and some data are siloed completely. This fragmentation of data across different jurisdictions prevents unified surveillance.

All the barriers discussed here have a common root cause in the years of funding neglect and the struggle to appropriately staff public health agencies in America. For decades, public health has been subject to cycles of boom-and-bust funding, where emergencies like SARS will bring in a glut of funding, only to disappear once the problem has passed. One example of the boom-and-

bust funding cycle was a \$918 million investment in public health emergency preparedness programs in 2002 following the 2001 anthrax attacks. By 2022 the yearly investment was \$715 million, a 48% reduction after inflation (McKillop 2022). Without consistent funding, preventative measures like modernizing technological systems and expanding the public health workforce are not completed. The public health system ossifies and cannot prepare adequately for the next emergency or even meet its fundamental goals. In the decentralized US system, funding is uneven across jurisdictions and subject to radical cuts without warning. Most importantly, without funding the tech systems that allow data collection and sharing cannot be updated and maintained sufficiently.

It is estimated that the US public health system had a shortage of 250,000 workers in 2020. Beginning during the 2008 recession, governmental public health lost around 19% of their workforce with some states, like Pennsylvania, having higher rates of around 24% (Wilson, Troisi, & Gary-Webb, 2020). Many of these jobs were never replaced and the strain placed on the remaining workforce during the pandemic is causing burnout. One in three public health employees are considering leaving their current organization according to the Public Health Workforce Interests and Needs Survey (Sellers et al., 2015). 49% and 41% reported low pay and work overload, respectively, as a reason for wanting to leave. Boom-and-bust funding cycles prevent wages from increasing and new hires from helping reduce workload.

Surveillance is one of the systems most affected by the workforce deficit according to the CDC, “Serious public health workforce shortages exist in disciplines that perform surveillance functions, and these shortages limit the nation’s capacity and plans for enhancement (Drehobl, Roush, Stover, Koo, & Centers for Disease Control and Prevention, 2012).” The public health workforce needs data scientists, information technology experts, computer scientists, and other

highly skilled workers to create and maintain effective surveillance systems. Attracting these workers is a crucial barrier to surveillance initiatives in the US.

The CDC's commitment to addressing these barriers in the Data Modernization Initiative (DMI) is highly significant. The result of years of work prior to the COVID-19 pandemic, DMI is an expansive modernization program with funding and congressional backing. The program seeks to address many of the critical barriers that exist in US public health including outdated technology, a diminished workforce, and more. DMI is working to solve these barriers in the US public health environment, which is very different from Scandinavia. This paper will explore the surveillance systems in Nordic countries, where many of these barriers do not exist, to provide an outside perspective on the possibilities of a more centralized surveillance system. First, it is important to outline the types of systems in the US.

## **1.2 Surveillance Systems in the US**

In modern public health, surveillance systems function through passive or active data collection—or a combination of both. Broadly, the sources of public health data come from six areas: single or small series case reports, vital statistics and reportable diseases, surveys, self-reporting, sentinel monitoring, and syndromic surveillance (Riegelman & Kirkwood, 2015). Small series case reports are data from clinical care provided to individuals. Vital statistics are crucial data related to births, deaths, marriages and more. Sentinel surveillance uses a small number of key data collection sites to monitor larger trends. Finally, syndromic surveillance tracks symptoms of a particular health concern rather than a lab test to detect trends earlier than otherwise possible. Details are provided below on how several key systems in the US collect and report data.

Notifiable disease surveillance systems require clinicians and laboratories to immediately report specific diseases, usually highly communicable or novel diseases, to public health authorities at the time of diagnosis. Some examples of notifiable diseases include anthrax, HIV, and measles. The list of notifiable diseases varies by state and jurisdiction because it is at these levels that laws on reportable diseases are passed. For example, “reporting of coccidioidomycosis to CDC is not done by some states where this disease is not reportable to local or state authorities (CDC.gov).” In the US, the National Notifiable Disease Surveillance System (NNDSS) is run by the CDC in partnership with the Council of State and Territorial Epidemiologists (CSTE). Health departments in 50 states, New York City, the District of Columbia, and 5 U.S. territories (Guam, Marshall Islands, Northern Mariana Islands, Puerto Rico, and U.S. Virgin Islands) voluntarily report notifiable diseases to the CDC. NNDSS is an automated system and is reported in the *Morbidity and Mortality Weekly Reports* (MMWR), in the *Summary of Notifiable Diseases, United States*, and the NNDSS website.

The National Center for Health Statistics (NCHS) maintains the National Vital Statistics System (NVSS). This system tracks “vital events” including births, deaths, fetal deaths, marriages, and divorces. Included within this system are birth and death certificates which contain important health information including birth weights, demographic information, and cause of death. Like NNDSS, the states and territories are responsible for the collection of vital data but unlike NNDSS, they are required by The Health Services Research and Evaluation and Health Statistics Act of 1974 to report the vital statistics data to NCHS. NVSS data are reported electronically through National Vital Statistics Reports.

There are dozens of health registries in the US that collect information about specific conditions. They are maintained by government agencies, nonprofits, healthcare facilities, and



private companies. An illustrative example of a federal health registry is the National Program of Cancer Registries (NPCR). Run by the CDC, NPCR collects data from central cancer registries in 46 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and the U.S. Pacific Island Jurisdictions (Guam, American Samoa, Northern Mariana Islands, Federated States of Micronesia, Republic of the Marshall Islands, Republic of Palau). Each jurisdiction collects cancer data in their registry which feeds into the NPCR electronically. NPCR also provides participating registries with technical and funding support. Data from NPCR are compiled and published in the US Cancer Statistics database.

Like registries, there are numerous surveys for risk factors, health behaviors, and other determinants of disease. NCHS conducts many surveys that can be provider surveys or population surveys. Examples of provider surveys include the National Ambulatory Medical Care Survey and the National Electronic Health Records Survey. Population surveys include the National Health Interview Survey (NHIS) and National Health and Nutrition Examination Survey (NHANES). Using NHANES as an example, this survey collects information on demographic, socioeconomic, dietary, and health-related issues to determine prevalence of disease and risk factors. Data are collected through interviews in respondents' homes and measurements performed at mobile centers throughout the nation. Data are collected electronically but published bi-annually in data files on the NCHS and in scientific publications.

Despite many of these systems being electronically based, there is very little ability to link the data contained in one surveillance system with another. This is the issue of siloed information. With so many data sources reporting data collected using different methodologies using different systems at different speeds, accessing necessary information for analysis, interpretation, communication, monitoring and/or planning is challenging.

The CDC's Data Modernization Initiative (DMI) is in the process of improving each of these surveillance systems and addressing the barriers. For example, work is being done on improving NNDSS to allow for improved electronic case reporting (eCR). eCR, and the overall modernization process, that will decrease state and local health departments workforce and financial burden. For each of these key surveillance systems, DMI is exploring and executing ways to improve data collection, reporting, and analysis.

### **1.3 Surveillance During Public Health Emergencies**

Prior to the COVID-19 pandemic, experts believed the United States was one of the best prepared countries for global public health threats (Bollyky & Patrick, 2020). Due to a combination of factors, the US response to the pandemic was initially sluggish and disorganized both in terms of monitoring and assessment of the pandemic (i.e. in collecting information on the infectivity, pathogenicity and virulence of COVID-19) and in terms of reducing its spread (i.e., by dissemination of information on measures to be adopted to reduce the spread, offering testing, etc.), thus leading to an unprecedented number of infected individuals and preventable deaths. To fill the gap left by federal data collection, the primary source of COVID-19 case data was ad-hoc organizations like The COVID Tracking Project and private institutions like Johns Hopkins University. While the CDC eventually negotiated the necessary data agreements with states to reassert its position of authority on COVID-19 data, the delay resulted in preventable deaths and deepening distrust towards the public health system (Jin, 2021).

In public health emergencies particularly, the necessity for rapid data collection and reporting is more urgent. During emergencies like outbreaks, “surveillance is needed to

characterize health threats, track the health of affected populations throughout the course of events, and complement more targeted epidemiological and laboratory investigations” (Cookson & Buehler, 2014). To make effective policy, decision makers—be they in government or the private sector—require accurate and timely data. In public health emergencies, faster data means lives saved.

Since 2020, under intense pressure from multiple public health emergencies, the US failed to conduct adequate surveillance to meet the foundational goals of the public health system. Competing epidemics of opioid use disorder, teen nicotine use, COVID-19, and the danger of an emerging Mpox epidemic stress the system and highlight the need for significant improvements. Public health leaders have long warned these dangers existed, but after years of underfunding and neglect the nation’s public health system was ill prepared.

#### **1.4 Public Health in Nordic Countries**

Nordic Countries, namely Denmark, Finland, Iceland, Norway and Sweden, benefit from strong social welfare systems, consistent and sufficient healthcare investments, and coordinated overall public health strategies (Magnussen, Vranbaek, & Saltman, 2009). All Nordic countries have higher life expectancy (83.9 years) and lower burden of disease than the global average (Nordic Burden of Disease Collaborators, 2019). Health outcomes vary slightly across the Nordic region, but low rates of economic inequality and high levels of education are consistent and have been linked to better outcomes. Likewise, health systems vary slightly by country but shared overall priorities and goals ensure similar high-quality outcomes:

“Nordic countries share a common history, culture, economy, and social structure, as well as close geographical proximity, and thereby also a number of fundamental health policy ideas. The countries’ healthcare systems, like other social sectors, have been built on the principle of universality: all inhabitants have the same access to public health services regardless of social status or geographic location. Thus, the goal of equity has in the Nordic countries been closely related to equal access regardless of gender, age, place of residence, and social status (Magnussen & Martinussen, 2013).”

“The Nordic Model” is an opaque term often used to describe the political and economic system of Scandinavian countries. In a public health context it means that the provision of healthcare services is guaranteed to all residents with minimal cost and equitable access (Magnussen et al., 2009). Universal healthcare coverage is a key component of the Nordic Model of public health. 75-85% of the healthcare costs are covered by taxes with supplemental insurance covering the remaining costs.

The most important factor in Nordic public health surveillance is the personal identification number that each resident is assigned at birth or immigration. These identification numbers never change over a resident’s lifetime (except in rare occurrences) and link an individual’s data in healthcare, schools, finance, and taxation. Originally established for taxation purposes, these personal identification numbers now serve crucial health data tracking purposes (Laugesen et al., 2021).

## **1.5 Gaps in Knowledge**

In the US, surveillance is entering a new era of technological modernization, through programs like the Data Modernization Initiative, to meet the ever-evolving challenges in public

health. While this is long overdue in the US, other countries have engaged in surveillance modernization and operate very different systems. The Nordic health system is renowned for its universal access, high quality care, and overall health outcomes (Einhorn, 2019). While the healthcare delivery and social welfare system has been extensively researched, little is known about the public health surveillance strategies and systems in Nordic countries. This essay seeks to improve the understanding of the available literature concerning Nordic surveillance systems and the impact on the ability of public health workers to improve the health of populations.

### **1.6 Public Health Significance**

Public health faces many challenges today. Urgently, only 60% of Americans trust public health agencies to fulfill their foundational goals of protecting and promoting health (Harvard T.H. Chan School of Public Health, 2021). A key contributor to the rampant distrust of public health work was the failure to adequately respond to the COVID-19 pandemic. The barriers to effective surveillance in the US prevented proper analysis and communication of data. Improving surveillance improves epidemiology, which improves decision making which improves public trust. This is a critical issue to address. Without trust, public health cannot achieve foundational goals.

If these barriers to surveillance are removed, the work of epidemiologists in government and academia will become more efficient and effective. Epidemiologists will have access to more complete data faster and faster data saves lives. Many of the time-consuming tasks epidemiologists are used to, like extensive data cleaning, could be eliminated. These possibilities warrant the study of other surveillance systems mechanics for providing data to epidemiologists.

The basic goal of public health is to save lives and improve the quality of life of everyone. Even more important than improving public trust in public health institutions, improving the quality and speed of data helps healthcare workers and decision makers make better decisions, often saving lives.

## **2.0 Objective**

A traditional narrative literature review was conducted to assess the body of literature on the form and function of Nordic nation's public health surveillance systems. The review aims to identify how the Nordic surveillance systems impact the speed of decision making and the ability of public health professionals to monitor health concerns and outcomes. While the American public health system is taking steps toward a more integrated surveillance network, analyzing the Nordic surveillance systems can offer valuable insights into how better surveillance practices can improve population health outcomes. Identifying these best practices is valuable to the continued improvement of epidemiology practices and accomplishment of public health goals like saving lives.

### 3.0 Methods

#### 3.1 Search Overview

The literature search was conducted on *PubMed* (National Library of Medicine) through the institutional access provided by the University of Pittsburgh. The search took place on October 2<sup>nd</sup> – October 5<sup>th</sup>, 2022. The resulting search's citations were stored in *SciWheel* (SAGE publishing) and exported to an Excel workbook where search terms and strategies were tracked. The search strategy included MeSH terms, title, and keyword searches. Due to resource and time constraints, the search included only English language publications. However in Nordic countries, between 70%-90% of academic articles and papers are written in English so this is an inclusive data set (Gregersen et al., 2014). All study designs and review types were considered as long as they met the eligibility criteria. Search terms are detailed in the figure below.

Table 1 Line by Line Search of Pub Med Database

Line Number	Search String
1	("norway"[Title/Abstract]) OR ("sweden"[Title/Abstract]) OR ("finland"[Title/Abstract]) OR ("denmark"[Title/Abstract]) OR ("iceland"[Title/Abstract]) OR ("nordic"[Title/Abstract])
2	(registry [Title]) OR (survey[Title]) OR ("notifiable"[Title]) OR ("syndromic"[Title]) OR ("sentinel"[Title]) OR (vital stat*[Title]) OR ("active surveillance"[Title/Abstract]) OR ("passive surveillance"[Title/Abstract])
3	#1 AND #2
4	Surveillance systems AND modernization AND data AND europe
5	((("data sharing"[Title/Abstract]) OR ("data collection"[Title/Abstract])) OR ("data reporting"[Title/Abstract]) AND #1
6	data authority[All Fields] AND #1
7	#3 AND #5
8	((evaluat*[Title/Abstract]) AND ("surveillance"[Title/Abstract])) AND ("data"[Title/Abstract]) AND #1
9	#4 OR #6 OR #7 OR #8
10	#9 AND english[la]



### **3.2 Eligibility Criteria**

Studies were excluded if published prior to 2010. Surveillance systems change over time in form and function through modernization processes and expanding goals; thus, ensuring that the study was written recently ensured its relevancy. By 2010, technological systems like electronic reporting and cloud data storage, were available to create modern surveillance systems.

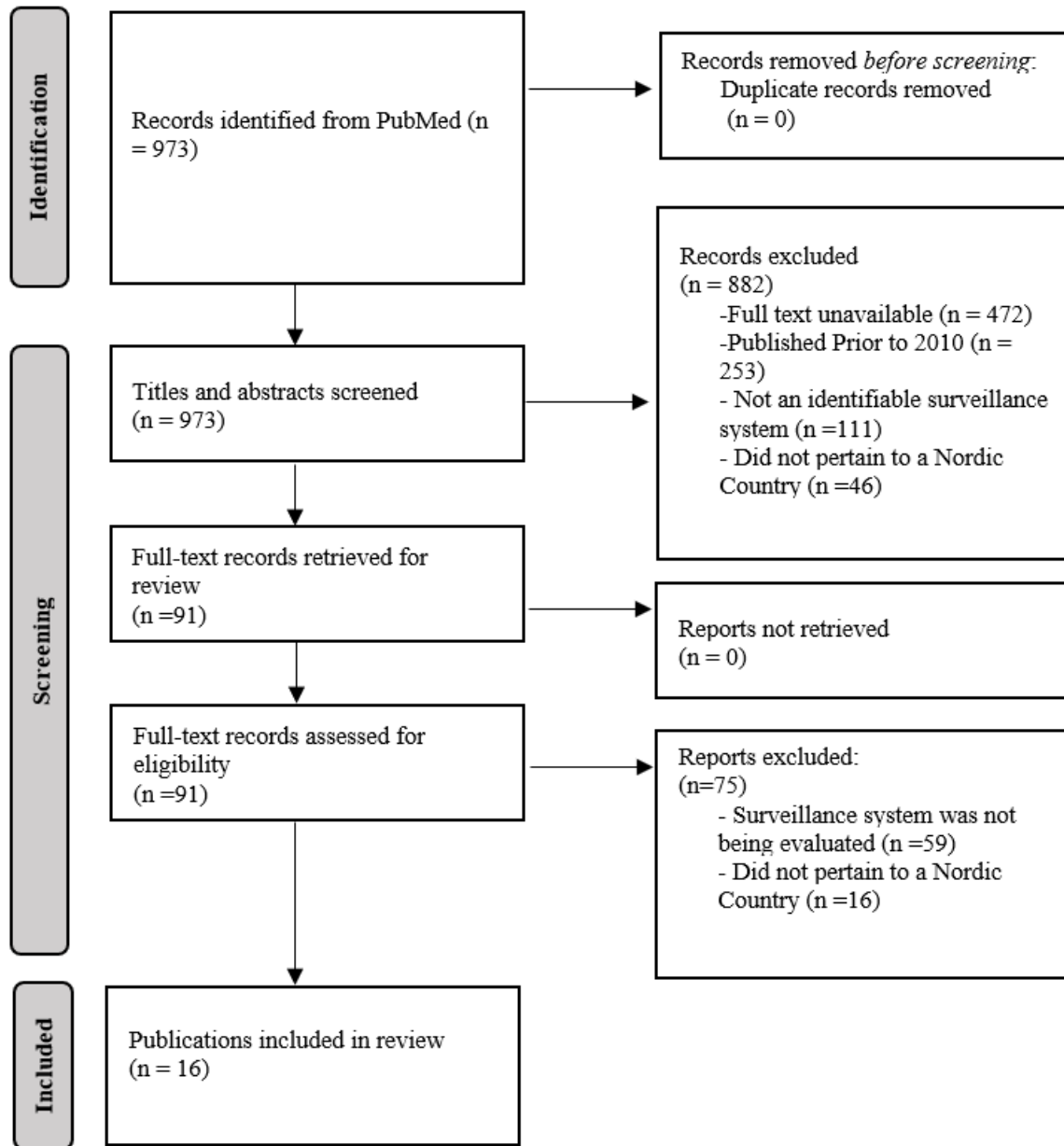
The search was limited to the form and function of identifiable surveillance systems (registries, surveys, notifiable diseases, etc.) or surveillance strategies. These systems have identifiable characteristics that can be examined in comparison to US systems. Studies involving surveillance strategies were also included as they detail overall differences in public health system structure.

Studies were included only if they pertained to Nordic countries: Denmark, Sweden, Finland, Norway, and Iceland. These countries share a common social and economic structure that influences their public health surveillance in similar ways. Studies that focused on Europe more broadly were included only if Nordic countries were discussed specifically.

### **3.3 Selection of Sources of Evidence**

A total of 973 records were identified from the PubMed search. 472 records did not have fully free texts available for review and were thus excluded. 253 records were published prior to 2010 and were excluded. 46 records did not pertain to Nordic countries and were also excluded. This left 96 full text records to retrieve and review. These 96 records were assessed for eligibility including if a surveillance system was being evaluated in its functionality to epidemiologists and

the previous criteria combined. 16 publications met all the criteria and were included in the literature review. A PRISMA flow chart of the process is presented in Figure 1.



**Figure 1 PRISMA Flow Diagram of Articles Included and Excluded from Literature Search**

## **4.0 Results**

### **4.1 Characteristics of Sources of Evidence**

For each included publication, author and year published, title, research aim, study design, surveillance system being evaluated, country of study, and findings were tabulated. Of the 16 studies included in the review, 7 evaluated surveillance systems in multiple Nordic countries, 1 studied system in Sweden, and 8 studied systems in Denmark. The types of surveillance systems studied were case reporting (1), registries (6), surveys (3), syndromic (1), notifiable disease (1), and multiple surveillance systems (4). Studies included in the review were published from 2014-2022. These characteristics are presented in Table 2.

**Table 2 Table of Included Publication Characteristics**

<b>First Author, Publication Year</b>	<b>Title</b>	<b>Research Aims</b>	<b>Study Design</b>	<b>System Type</b>	<b>Country</b>	<b>Findings</b>
<b>Alriksson- Schmidt, 2020</b>	Flaunting our assets. Making the most of the Nordic registry goldmine: Cerebral palsy as an example.	Describing the results of a Nordic cerebral palsy (CP) registry research program. The program combined data from different registries in new ways to improve registry research potential and study best practices for combining registry data.	Descriptive Analysis	Registry (Cerebral Palsy)	All Nordic Countries	By linking national CP registry data to other national registries, the research potential of the registries was improved. Linking registries allows research results to be applied at a population level which improves research validity. One crucial factor to the success of this kind of linkage is the standardization of data across different surveillance systems and jurisdictions.

<b>Bel-Serrat, 2017</b>	Inventory of surveillance systems assessing dietary, physical activity and sedentary behaviors in Europe: a DEDIPAC study.	Describing the current European surveillance systems that monitor diet, physical activity, and sedentary behaviors. The study seeks to strengths and identify gaps in the surveillance systems that need to be addressed to allow for an integrated European surveillance system.	Survey Analysis	All	Europe	Nordic countries have established common mandatory and standardized surveillance of dietary intake, dietary behaviors, physical activity, sedentary behaviors, alcohol consumption, tobacco consumption, anthropometry, and socio-demographic variables. This is a useful example of multi-national surveillance techniques.
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<b>Blanchard, 2022</b>	Comparison of national surveillance systems for Lyme disease in humans in Europe and North America: a policy review.	To identify and compare, 10 years after the European inventory, the characteristics of national surveillance systems and policies for Lyme Disease in humans, with additional countries.	Literature Review	All	Europe	National surveillance systems for Lyme disease vary across Nordic nations. Norway and Denmark have nationally administered systems while Sweden has only sentinel lab reporting without any established system. Denmark has pioneered electronic lab reporting for Lyme Disease. Norway aggregates lab and clinical data into a unified database through the use of personal identification numbers.
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<b>Chaine, 2017</b>	Description and validation of a new automated surveillance system for Clostridium difficile (CD) in Denmark.	The aim of this paper is to study the efficacy of a new automated surveillance tool monitoring Clostridium difficile (CD) using the Danish Microbiology Database (MiBa), and compare it to existing methods for CD.	Descriptive Analysis	Registry (CD)	Denmark	A new automated surveillance system for CD was more accurate than older, traditional surveillance systems. This study uncovered the number of CD cases in Denmark had been underreported significantly. MiBA-based surveillance can effectively replace the current system and improve the ability of epidemiologists to understand the disease.
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<b>Christensen, 2022</b>	35 Years of health surveys in Denmark: a backbone of public health practice and research.	This paper aims to describe the development, structure, and methodology of the national health surveys in Denmark as well as the application in public health practice and research.	Descriptive Analysis	Danish National Health Survey (Survey Data)	Denmark	The DNHS is useful across multiple levels of the Danish healthcare system for the comparison of research results at the national, regional, and local level. DNHS can do this because of standardized questionnaire content, timing, and methodology.
<b>Erlangsen, 2015</b>	Danish nationwide registers for public health and health-related research	Discussing the strengths and limitations of Nordic registry data for public health research and providing an outline of the different registries.	Descriptive Analysis	Registry	Denmark	The largest strength of Nordic registries is they provide data on every individual in the population with no loss to follow up. This allows research on rare events and in small populations. Linkages across registries are becoming more common and enabling new and improved research. Limitations



						include clinical observations being available for select populations.
<b>Genevieve, 2019</b>	Factors influencing harmonized health data collection, sharing and linkage in Denmark and Switzerland: A systematic review.	This systematic review aims to identify barriers and facilitators to health data harmonization- including data sharing and linkage- by a comparative analysis of studies from Denmark and Switzerland.	Systematic Review	All	Denmark	Denmark has created a system that relies on health registries. Through the use of personal identification numbers, the data linkage is excellent and barriers to data collection, access, and linkage are few.
<b>Jensen and Lyng, 2018</b>	Establishing a Nation-Wide Infrastructure for Systematic Use of Patient Reported Information	To describe the development of a common national infrastructure for surveys in Denmark through IT infrastructure and standardized data.	Program Implementation Review	Surveys	Denmark	Conducting patient and provider workshops increases the ability of the survey to rapidly collect and distribute data to

						public health agencies.
<b>Laugesen, 2021</b>	Nordic Health Registry-Based Research: A Review of Health Care Systems and Key Registries	To review Nordic Health Registry coverage and limitations from a practical and legal perspective and to describe potential for cross-border data sharing.	Review	Registries	Nordic Countries	Unique personal identification numbers, assigned to all people in Nordic countries, allows researchers to obtain extensive health data from birth to death. The registries these data are recorded on allow for easy data exchange and sharing so researchers can compare populations across borders. Overall, universal identification numbers and Nordic registries are a “gold-mine” for population health research.

<b>Lyng, 2019</b>	A Paradigm Shift: Sharing Patient Reported Outcome via a National Infrastructure	To evaluate the modernization of Danish patient outcome survey data.	Program Implementation Review	Surveys	Denmark	IT modernization is crucial to the development of effective survey systems. Denmark has applied international data standards to their survey data to improve data sharing and reporting.
<b>Maret-Ouda, 2017</b>	Nordic registry-based cohort studies: Possibilities and pitfalls when combining Nordic registry data	To describe and evaluate the ability of researchers to use Nordic registries to conduct cohort studies.	Literature Review	Registries	Nordic Countries	Nordic registries allow for researchers to combine data from multiple countries and create large research cohorts. Obtaining permissions from each country remains the largest barrier.

<b>Ma, 2014</b>	Syndromic surveillance of influenza activity in Sweden: an evaluation of three tools	To evaluate syndromic surveillance tool's ability to track influenza in comparison to other surveillance tools in Sweden.	Retrospective Study	Syndromic	Sweden	Swedish syndromic surveillance tools (including web query and medical hotline statistics) are effective complements to traditional surveillance mechanisms in reflecting influenza patterns.
<b>Pottegard, 2020</b>	Existing Data Sources in Clinical Epidemiology: The Danish COVID-19 Cohort.	To establish a prospective cohort of all Danish residents tested for SARS-CoV-2 in Denmark and evaluate its utility in epidemiological research.	Prospective Cohort Study	Notifiable Disease Surveillance	Denmark	The Danish COVID-19 cohort was able to include all Danish residents with a PCR test for COVID-19 and, through linkage to health registries, provides extensive data for epidemiologic research.
<b>Pukkala, 2018</b>	Nordic Cancer Registries – an overview of their procedures and data comparability.	To compare the Nordic Cancer Registries to determine if their differences explain differences in cancer	Systematic Review	Registry (Cancer)	Nordic Countries	The similarities of Nordic registries make data from these countries more similar than any other five countries, but

		incidence rates across Nordic countries.				slight differences in collection do create differences. All Nordic Cancer Registries provide high quality data.
<b>Skovgaard, 2022</b>	Data authority: Public debate about personalized medicine in Denmark	To analyze the public discourse in written in Denmark around personalized medicine and health data authority.	Literature Review	All	Denmark	Danish public opinion largely supports data authority in public health surveillance. There are disagreements as to what degree the system is able to collect information but overall, there is broad support. The Danish healthcare system already has a great degree of data authority through personal identification numbers.

<b>Verberk, 2022</b>	Automated surveillance systems for healthcare-associated infections: results from a European survey and experiences from real-life utilization	To describe the structure and design of automated surveillance systems and their implementation in healthcare institutions in different regions of Europe.	Descriptive Analysis	Case Reporting	Nordic Countries	Danish automated surveillance (AS) systems are nationally established and have automated reporting with structured data from registries providing complete information. Swedish AS improved sensitivity by over 85%. AS systems reduced workload for hospital staff and were had higher sensitivity compared to manual systems. Principal barriers of implementation were strict data security regulations as well as creating and maintaining an information technology infrastructure.
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## **4.2 Results of Individual Sources of Evidence**

The following sections will detail the literature included in this review. The results are structured into the types of surveillance systems that the sources are primarily researching. The first section focuses on registries, which results show are the most common, and therefore, the most studied type of surveillance system in Nordic countries. Surveys, syndromic, and other kinds of systems, which often link to registries, are also included and are detailed next. Finally, the last section focuses on the results from the literature that discusses important issues around data collection, data sharing, and policy that play a critical role in surveillance systems. These sections will explain the results that pertain to the questions this review aims to resolve, i.e., what types of surveillance systems are used in Nordic countries and why; what barriers they face and whether they are similar to barriers in the US; whether they have overcome barriers present in the US; particular examples of success; and whether the systems are technologically modernized and easy to use. These questions are fully explored in the discussion **section**, but these studies directly address them.

### **4.2.1 Nordic Registries**

Six of the sixteen articles included in the literature review focused on public health registries (Alriksson-Schmidt et al., 2020; Chaine et al., 2017; Erlangsen & Fedyszyn, 2015; Laugesen et al., 2021; Maret-Ouda, Tao, Wahlin, & Lagergren, 2017; Pukkala et al., 2018). Alriksson-Schmidt et al. (Alriksson-Schmidt et al., 2020) studied a network of cerebral palsy (CP) registries (CPUP/CPRN/CPOP) across all Nordic countries. Their aim is to combine data from these different national CP registries and analyze if this type of linked multi-national registry

would be useful for future research. This research is ongoing, so the paper describes the early experiences of the cross-border data merging process. A team of 17 researchers expects to use registry data from 8,000 individuals with CP across Sweden, Norway, Denmark, Iceland and Finland. The authors evaluated the ability of the registry to collect accurate information, the efficiency by which researchers could access data, as well as ways the new registry could improve. The study concluded that the Nordic CP registries are strong tools for epidemiologists and can serve as a model for other registries. The registries are interoperable and use standardized data systems, meaning data can be easily combined and analyzed. The key was having nearly identical protocols for data collection, which makes the systems very similar. The main obstacle was the time-consuming process of obtaining individual permissions from each country. If research is done within a single Nordic country, this process is significantly expedited, but cross border research presents additional hurdles. While this process can be improved, the basic and necessary infrastructure is there for efficient and useful cross border linkage and surveillance (Alriksson-Schmidt et al., 2020).

Chaine et al. studied a new automated surveillance system (MiBa) for *Clostridium difficile* (CD) registries and found it was more accurate than older, traditional surveillance systems. “MiBa is a real-time database that automatically collects microbiological test results from each Danish Department of Clinical Microbiology (DCM) at the time the electronic report is sent to the physician who requested the analysis (Chaine et al., 2017).” This study uncovered that the number of CD cases in Denmark had been significantly underreported in the past and that MiBa-based surveillance can effectively replace the current system, improving disease estimates in the population and allowing research opportunities that would aid in the understanding of this disease. The study did not examine the costs of implementing an automated system but over time it would



eliminate the man hours required to manually input the data. This study showed that automated surveillance is quicker and more accurate than manual processes that characterize traditional data collection methods and can be expanded to other applications and diseases (Chaine et al., 2017).

Erlangsen and Fedyszyn assessed the broader strengths and limitations of registries in Denmark. The population registers record full demographic data such as home address, marital status, education level, income, etc. The health registers record all clinical medical records from the free public healthcare system including general practitioners, somatic hospitals, psychiatric hospitals, prescriptions, and death data. Private hospitals are also required to report all data on their patients as well. The study evaluated health and population registers and how they interacted with one another. This study found that the personal identification numbers all Danish residents receive allow the uniform linkage of registry data on an individual level that improves their efficacy. The strengths of the registries are that the data are fully representative of the entire population with no loss to follow-up. Registries are also fully representative in Denmark so sample sizes are large when using them for epidemiological research (Erlangsen & Fedyszyn, 2015).

Laugesen et al. conducted a review of Nordic healthcare systems and the coverage of public health registries. This study found that all the Nordic healthcare systems in each country deliver data routinely to health registries, of which there are many (200 in Denmark alone). The personal identification numbers assigned to each resident are critical to registry based surveillance as they “enable easy, accurate, and unambiguous individual-level linkage of data (Laugesen et al., 2021).” Furthermore, registries provide complete follow up to reduce selection bias and have large sample sizes that allow the study of rare exposures. Finally, registry data are readily available and reduces the time and financial burden on epidemiologic research. This review also expanded on the limitations and differences between the registries in each country. While the data is standardized

nationally, differences in classification and coding exist between countries. For example, each country adopted ICD-10 at different times between 1994 and 1999. In comparison to other systems these differences are minor, but researchers must take these limitations into account when planning cross-border research. The review points out that researchers can minimize this issue through organizations like NordForsk that facilitate data-sharing and transfer. Additional barriers exist to cross-border research including obtaining permissions from each country—similar to obtaining permissions from each state in the US—and the cost of data processing. As the US is attempting to streamline the process of data sharing between states, Nordic countries are exploring ways to create a more transparent and accessible data sharing framework (Laugesen et al., 2021).

Maret-Ouda et al. studied all five Nordic countries (Denmark, Finland, Iceland, Norway and Sweden) and their nationwide registries' impact on public health research. They found the registries have a similar data structure and validity linked through the personal identification number (PIN), allowing for large registry-based cohort studies with long and complete follow-up. PINs allow for data linkage at the national level, but it is also useful for cross border surveillance because “collaborative legislation also makes it possible to follow individuals moving between Nordic countries by means of the personal identity numbers.” Cross border data linkage is easier than in other areas of the world through their similar data classification structures. One example of similar structures is that Nordic countries have agreed since the 1990's to code all surgical procedures in the same way. Differences do exist, each country adopts ICD classifications at different times, but overall Nordic countries are ahead of the US in data standardization in their registries. For cross-border studies, permissions must be obtained from each country with differing requirements. Once obtained, the researcher will need to account for differences in data formats but through a pseudo-anonymized number derived from the PIN, the data can be more easily

merged. While data cleaning is still necessary in some cases, this study found that these registries decrease the burden of time and cost on epidemiologists and provide an excellent source of data for cohort studies across the Nordic countries (Maret-Ouda et al., 2017).

Pukkala et al. conducted a systematic review of cancer registries across all Nordic countries. This study described characteristics of the registries, their data sources, and coding systems. Important results from this study were that cancer registries across the Nordic countries have complete, high-quality data, which links with other health and population registries. Denmark and Finland are using automatic electronic reporting systems while Iceland, Norway and Sweden only have electronic reporting. Key data sources for these registries are public hospitals, private clinicians, labs, and vital statistics. All of these source's report standardized data to their respective national registries. (Pukkala et al., 2018).

#### **4.2.2 Nordic Surveys**

Three of the studies investigated Nordic survey systems (Christensen, Lau, Kristensen, Poulsen, & Breinholt Larsen, 2022; Jensen & Lyng, 2018; Lyng, Jensen, & Bruun-Rasmussen, 2019). Christensen et al. based their research on six random subsamples of Danish adults (approximately 6% of the population) in each of the five administrative regions of Denmark and one national sample. Data was collected via a web questionnaire or through a paper questionnaire. This study evaluated the DNHS, the Danish National Health Survey, which collects data from the general population on health-related issues. This study found that the DNHS provides broad and timely data to public health decision makers through the use of the personal identification number system. The data are highly useful for policy development and behavioral based interventions such as tobacco cessation and alcohol consumption interventions. The survey has been highly useful to

public health research for its linkage to health registries (again through the personal identification numbers) (Christensen et al., 2022).

Jensen and Lyng, 2018 detail a Danish surveillance system for patient reported outcomes and its evaluation through patient participatory surveys. Using the patient reported outcome (PRO) questionnaire, this study sought to determine if conducting patient and provider workshops increases the ability of the survey to rapidly collect and distribute data to public health agencies. Results suggest that this participatory design did increase the efficacy of the survey system. The standardization of the data reporting was accomplished through adoption of Danish versions of the HL7 standards (health level 7). HL7 is a set of international recommendations for standardized health data transfer, which Denmark has successfully implemented. (Jensen & Lyng, 2018). HL7 is being adopted in the US now but requires voluntary buy in from healthcare providers, insurers, and states which Denmark has already completed.

Lyng further explored the PRO surveillance potential in a 2019 paper that sought to evaluate the modernization efforts of Danish survey data. Lyng found that IT modernization is crucial to the development of effective survey systems, and Denmark has developed effective IT infrastructure in the last decade. Denmark has a common national infrastructure for electronic health records (EHR) to share data quickly with researchers and clinicians. The EHR framework relies on patient reported information that is later communicated to the national surveillance infrastructure through “Cross-Enterprise Document Sharing”. This system uses international data reporting standards (HL7 standards) which allow the faster dissemination of findings and, subsequently, also their application in clinical practice (Lyng et al., 2019).

One study conducted a survey of clinicians, public health workers, and data scientists on the effectiveness of specific surveillance systems. Bel-Serrat et al. studied the 50 systems that

study dietary and physical activity behaviors across multiple EU countries, including Nordic countries. This study was the first inventory of surveillance systems for these behaviors in Europe. The *Nordic monitoring of food, physical activity, and overweight* is a regional surveillance initiative that the study specifically assessed. The study found that Nordic countries have established common mandatory and standardized surveillance of dietary intake, dietary behaviors, physical activity, sedentary behaviors, alcohol consumption, tobacco consumption, anthropometry, and socio-demographic variables (Bel-Serrat et al., 2017).

#### **4.2.3 Syndromic, Notifiable, and other Nordic Systems**

One study included in the review focused specifically on syndromic surveillance in Sweden. Ma et al. evaluated three syndromic surveillance systems for influenza, to determine if these systems can serve as a more rapid indicator of flu trends over traditional surveillance—sentinel reporting and lab confirmed tests. This study was a retrospective statistical analysis that compared each syndromic surveillance system to each traditional tool and then the traditional tools to each other. The three syndromic tools were web query, medical hotline statistics, and school absenteeism. Web query (monitoring trends in search data) and medical hotline statistics were shown to be accurate reflections of influenza patterns, whereas school absenteeism was not. These new syndromic systems are automated and complement traditional sentinel surveillance for flu in Sweden (Ma, Englund, Bjelkmar, Wallensten, & Hulth, 2015).

Pottgard et al. studied Danish notifiable disease surveillance systems for COVID-19 that included all Danish residents that had tested positive for COVID-19 up to the study date and sought to evaluate the utility of the surveillance system in epidemiologic research. The data came from lab test results that are automatically reported electronically to a communicable disease registry as

well as nationally run prevalence studies. Pottegård found the system was linked effectively to Danish registries through the personal identification number and thus the data were highly valuable to epidemiologists. Furthermore, the Danish Microbiology Database (MiBa) was found to be an effective complement to this cohort. MiBa is a real time electronic lab result reporting system that sends communicable disease results directly to the notifiable disease databases. Both systems are nearly instantaneous, MiBa and the COVID-19 cohort report data twice daily to the Statens Serum Institut. There are no data privacy issues in these systems as the Danish Health Data Authority anonymizes the linked data and does not publish individual identifiable information (Pottegård et al., 2020).

Another study of notifiable communicable disease surveillance was performed by Blanchard et al. This study was a literature review on the Lyme disease (LD) surveillance systems of 34 countries including all five Nordic nations. The study found that national surveillance systems for Lyme disease vary across Nordic nations. Norway and Denmark have nationally administered systems, while Sweden has only sentinel lab reporting without any established system. Denmark has pioneered electronic lab reporting for LD, which decreases the necessary resources for surveillance. Norway aggregates lab and clinical data into a unified database through the use of personal identification numbers. (Blanchard et al., 2022). This is one case where the Nordic countries vary in their collection practices. There are particular strengths that this study acknowledges, such as electronic reporting in Denmark but the variability of the processes between countries warrants further study. Overall, cases are still recorded in infectious disease registries but there is not a standard registry for LD in each country. In the US, LD is one of the notifiable diseases in NNDSS, but collection practices and data protocols differ by state.

#### **4.2.4 Data Collection and Sharing**

Four of the reviewed publications focused on broader issues around health data collection and sharing including data authority, interoperability, and automated surveillance.

Automated systems across all Nordic countries were studied in detail by Verberk et al. This study described the design of automated surveillance systems in healthcare facilities. Automated systems for reporting electronic health records (EHR) decreased workloads for Nordic hospital staff and led to better patient care. The study found that maintaining the IT systems and preserving strict data security were barriers to automated disease reporting systems. The level of automation also varies across countries; Denmark extensively uses automated reporting and relies heavily on the registry system to collect and disseminate the data. Automated reporting is less prevalent in Sweden and Norway (but more than comparative regions) although new laws are seeking to improve data sharing (Verberk et al., 2022). Automated and electronic reporting is currently expanding also in the US but a significant amount of data from labs, health departments, providers and insurers is manually recorded and transmitted. It is only recently that much of the data the CDC collects from states switched from paper faxes to electronic datasets. The US certainly has the resources and expertise to implement automated systems, it needs only sufficient funding and urgency.

Skovgaard and Hoeber analyzed the public debate around personalized medicine and the debate around data authority in Denmark. This study found that Denmark prioritizes data privacy for commercial uses while prioritizing the linkage of data across registries. The Danish public largely agrees that data collection and sharing for the purpose of health benefits the population. This article also details several key structures of the data collection process in Denmark including that public health research using registry data is exempt from consent requirements and the Danish

healthcare sector is among the most digitized and data rich systems in the world (Skovgaard & Hoeyer, 2022).

The final study included in the review was conducted by Genevieve et al. The authors conducted a systematic literature review in order to identify barriers and facilitators to health data harmonization-including data sharing and linkage-by a comparative analysis of studies from Denmark and Switzerland. The review identified 6 key barriers to health data sharing: Ethico-Legal, Technical, Financial, Political, and Sociocultural. The authors found that ethical-legal barriers were virtually nonexistent in Denmark, due to the personal identification number system. Technical issues like data standards remain a barrier but these systems are making significant progress. Other technical barriers are reduced by the PINs. By relying heavily on registries, Denmark lowers the financial burden placed on researchers (Geneviève, Martani, Mallet, Wangmo, & Elger, 2019).



## **5.0 Discussion**

### **5.1 Summary of Findings**

Nordic surveillance systems vary slightly across countries but follow a similar structure. Personal identification numbers feed all health data into health registries and other surveillance systems. Health registries form the foundation of surveillance through the inclusion of virtually every resident from birth to death. Surveillance is coordinated at the national level with ministries of health monitoring data collection and dissemination. Data are reported into surveillance systems through electronic health records, electronic lab results, surveys, and other participatory designs that are connected to the registries. Innovations in automated reporting are proving to be effective and will likely replace traditional manual reporting completely. Data standardization across international lines is an ongoing process in the Nordic states, and it's more effective than any other region of the world, but within their own borders, data standardization is very high. Adoption of HL7 standards is beginning and this will help address the international data sharing barriers. Overall, Nordic states have highly interoperable surveillance systems that provide complete, rapid data to clinicians, researchers, and the public. The personal identification numbers that link health and administrative registries provide unparalleled data linkage for public health research and clinical providers. Nordic surveillance systems are built on the foundation of registries which is completely different than US surveillance. While similar technological barriers exist to modernizing systems, using registries as a foundation bypass many of the most significant problems faced by US modernization efforts.

## 5.2 Personal Identification Numbers and Registries

The greatest strength of the Nordic surveillance model is the personal identification number (PIN) that residents are assigned at birth or immigration. These numbers were continually cited as the foundation for the Nordic surveillance system. These numbers provide health data with linkage to housing, taxation, demographic, and all other data that researchers must go to great lengths for in the US. Furthermore, these PINs are permanent and follow an individual until death so there is no loss to follow up for these registries. This fact alone is very significant for the work of epidemiologists. PINs allow doctors from different practices or healthcare systems to access the same medical records, so if a patient moves or is unable to communicate their medical history, it is available (Different EHR systems also contribute to this problem in the US but current efforts, like DMI, are pushing for EHR interoperability). In Denmark for example, PINs have allowed clinicians access to health data from a single centralized system since 2010. Researchers are also able to use that system for de-identified data.

In America, the idea of a standardized PIN for healthcare is commonly referred to as a universal patient identifier (UPI). Developing a national UPI system has been proposed since the 1990's. In 1998, concerns over privacy and cost caused a ban of federal funding of a UPI (VanHouten & Brandt, 2021). This research shows that PINs are not only safe and highly useful for public health, but also widely supported by the populations that have actually used them (Skovgaard & Hoeyer, 2022). Privacy concerns are not a barrier to using PIN linked data in Nordic countries due to the de-identification of data when used in research. Identifiable characteristics like name are separated from the data leaving only a number with a full medical history.

It is because of these PINs being so effective and secure, that Nordic systems rely so heavily on registries for all forms of surveillance. In the US, registries are considered slow and

costly systems that researchers can use for good data but not timely data. In the Nordic model, these registries are digitized, interoperable, and reflect even better data quality than the US versions. The PIN based health registries represent 100% of the Danish population and thus allow for large sample sizes and rare exposures to be evaluated. The research firmly established that registries reliant on electronic health data transmitted rapidly and automatically, are excellent sources of data for epidemiological research and can be highly effective in emergency situations like COVID-19 (Pottegård et al., 2020).

It would be challenging and politically fraught to create a UPI in the US. But this research shows that when done properly, UPIs improve patient care and public health research significantly. The US could begin to expand the system of registry-based surveillance, like they have in Nordic countries, that would allow rapid and complete data collection and sharing. Researchers would have access to enough data that would help address things like sample size and diversity. While significant progress can and is being made to modernize current US systems, a UPI would expand the possibilities dramatically.

### **5.3 Surveillance Barriers in the Nordic Context**

The literature review identified several surveillance barriers for Nordic states. The Nordic model does struggle with the same barriers as the US, but technical barriers present more issues for Nordic countries while political and structural barriers hamper the US. American public health remains a model for technical innovation with one study detailing the US National Institutes of Health *Strategic Plan for Data Science* as a role model for technical modernization vision (Alriksson-Schmidt et al., 2020).

Skovgaard et al. produced an analysis of the data authority debate in Denmark which suggests that this issue, which is so prevalent in the US, does not elicit the same response in Nordic nations. With the accepted use of PINs, Scandinavians have established a data rich state with protections for individuals' data rights and privacy. The Nordic countries also do not suffer from a decentralized public health system. Across the region, surveillance responsibility and authority lie with the national level health agencies (Blanchard et al., 2022). There are benefits to the American public health system where jurisdictions can try new policies and tailor interventions to their populations, but surveillance is a practice that must be coordinated at a national level. Disease does not respect borders and without nationally coordinated data collection, trends and patterns are missed or seen too late.

Overall, the Nordic surveillance systems face many of the same technical challenges to modernizing surveillance. There does not seem to be a single organization, leader, or initiative that is pushing surveillance modernization in Nordic countries. They are trying to solve similar problems but instead of building new systems and negotiating buy in from countless entities, Nordic countries build on the existing robust PIN/registry system.

#### **5.4 Strengths, Limitations, and Directions for Future Research**

This literature review provides strong evidence through the use of a structured search methodology, the inclusion of a wide range of all designs and reports, and inclusion of only relevant and up to date information (2010 onwards). The results from these studies overall supported each other consistently across study designs.

This literature review has several limitations. While the majority of research published in Nordic countries is published in English, around 20% is not. These missing publications may offer highly relevant research and thus it is a limitation. PubMed was the only database searched for this review. There may be a better database to search for international research studies and this may affect the breadth of the review. The quality of research on this topic was also a limitation. For a research question on the structure and performance of systems, there are few statistical outcome measures and research designs are varied. There was little research devoted to the structure and function of surveillance systems. Research on surveillance systems also focused heavily on Denmark which left out many Nordic systems to compare to. Finally, there was a single reviewer.

This literature review was effective in addressing most parts of the research question. Considering the limitations outlined above, future research should address gaps in knowledge by evaluating more countries, delving deeper into the technical data sharing structures, collecting information on more types of surveillance systems, and conducting further research on how these systems impact the work of epidemiologists.

## 5.5 Conclusion

Overall, surveillance systems are an understudied field, at least from the perspective of tangible health outcomes. The importance of these systems in how they collect, report, and use data has become more apparent, as their value in improving public health increases. In the US, many technical, political, and cultural barriers have prevented the modernization of public health surveillance. In Scandinavia, unique administrative systems have created an environment rich in public health data for epidemiologists and clinicians to access quickly and cheaply. Numerous, robust registries that are connected to surveys, syndromic surveillance, notifiable disease, and other data systems, form the foundation of Nordic surveillance. For the US to achieve the same depth of health data, renewed consideration of developing a national UPI system to mirror the Nordic PIN system is critical. With faster and more complete data, the field of public health would benefit significantly through better interventions, better research, better responses, and greater public trust.

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