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____ **April 17, 2023**

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Legal and Ethical Issues to Modernizing Public Health Surveillance Supported by a Private Entity

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Abstract

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In the United States, public health surveillance (PHS) data are collected through thousands of reporting units at the local, state, territorial, tribal, and federal levels. Governance, collaboration, informatics, and analytics all face difficulties. As evidenced by PHS shortcomings during the COVID-19 pandemic, these problems are ongoing and extremely concerning. Therefore, a group of public health professionals proposes to pilot a new, Data-entry Once, One Health, Integrated Disease Surveillance and Response (IDSR) Health Information System (HIS) to modernize US PHS supported by a private entity contracting with the Centers for Disease Control and Prevention (CDC). Working together to establish this public-private partnerships (PPP) has potential value, but legal and ethical issues must be addressed first. Legal and regulatory frameworks (such as HIPAA and HITECH), consent, data ownership, conflicts of interest, discrimination, and public trust are among the concerns addressed. We seek to investigate the legal and ethical issues to modernizing PHS supported by a private entity in the United States. Qualitative research was conducted in PubMed™ and Google Scholar™, and thirty-seven resources were reviewed. We must carefully evaluate and handle the legal and ethical issues to guarantee that this new data endeavor benefits public health while protecting individuals' rights and wellbeing.

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Tables and Figures

Abbreviations

PHS	Public Health Surveillance
IDSR	Integrated Disease Surveillance and Response
HIS	Health Information System
CDC	The Centers for Disease Control and Prevention
AWS	Amazon Web Services
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health
EMR	Electronic Medical Records
IT	Information Technology
ONCHIT	Office of the National Coordinator for Health Information Technology
HIV	Human Immunodeficiency Virus
PPP	Public-Private Partnerships
ACD	Advisory Committee to the Director

Chapter 1: Introduction

Background and Significance

In the United States, public health surveillance (PHS) data are collected through thousands of reporting units at the local, state, territorial, tribal, and federal levels. There are challenges in governance, collaboration, informatics, and analytics. These issues are persistent and very troubling, as seen by PHS failures during the COVID-19 pandemic. Therefore, a group of public health professionals proposes to pilot a new, Data-entry Once, One Health, Integrated Disease Surveillance and Response (IDSR) Health Information System (HIS) to modernize US PHS supported by a private entity contracting with the Centers for Disease Control and Prevention (CDC).

The infrastructure (cloud-based “plumbing”) needed for this project is not publicly available. Therefore, the team envisions working with the private entity Amazon.

Amazon has a cloud-based “plumbing” called Amazon Web Services (AWS). AWS “replaces IT infrastructure, lowers time and effort for most companies, provides agility and instant elasticity that allow for minimizing and maximizing applications, is open and flexible in allowing users to choose what development platform or programming model is used, and maintains a secure network that ensures data privacy and security.” [1]

There is potential value in working together to set up this public-private partnership, but legal and ethical problems must be solved first. These issues include legal and regulatory frameworks (like HIPAA and HITECH), consent, data ownership, conflicts of interest, discrimination, and public trust.

Unquestionably, PHS has not reached its full potential in recent years and should be modernized. Public-private partnerships (PPP) can aid public health initiatives.

Modernizing PHS with the help of a private organization could be the answer to the needed change. To implement such an innovative program, many legal and ethical concerns must be addressed and considered.

Purpose Statement

This thesis will support concepts to modernize PHS in the United States. The proposed solution is a Data-entry Once, One Health, Integrated Disease Surveillance and Response (IDSR) Health Information System (HIS) to modernize US PHS supported by a private entity. This literature review addressed the legal and ethical issues to modernizing PHS supported by a private entity.

Research Questions

- What are the legal issues to modernizing PHS supported by a private entity in the United States?
- What are the ethical issues to modernizing PHS supported by a private entity in the United States?

Chapter 2: Methods

Analyzing qualitative methods was the most appropriate approach to answer the research questions. Literature was found through two primary sources: PubMed™ and Google Scholar™. Article inclusion criteria include publication on or after Jan 1, 2005, with full-text available, and published in English due to the vast range of topics considered. Thirty-seven resources were reviewed, and EndNote™ managed references and citations.

Chapter 3: Literature Review

1. Modernizing Public Health Surveillance (PHS)

Current PHS strategies have failed to ensure the safety of the population in recent years. Significant flaws in the infrastructure and procedures for PHS have come to light due to the COVID-19 pandemic. The need to modernize PHS is greater than ever. Public health has long been reliant on PHS. The gathering and sharing of PHS data influences public policy, national security, global economies, and people's health behaviors. [2] Modernizing PHS can lead to many positive outcomes that can lead to better health outcomes for the population.

Current methods of PHS involve a variety of collected data led by the nation’s leading public health agency, the U.S. CDC. The current methods rely on manual data entry and disease-specific monitoring, which puts an enormous strain on local, state, and federal data contributors. Because the tools and data are not interoperable, state and local reports to the CDC are frequently delayed. [2] Figure 1 illustrates a sample flow of public health data.

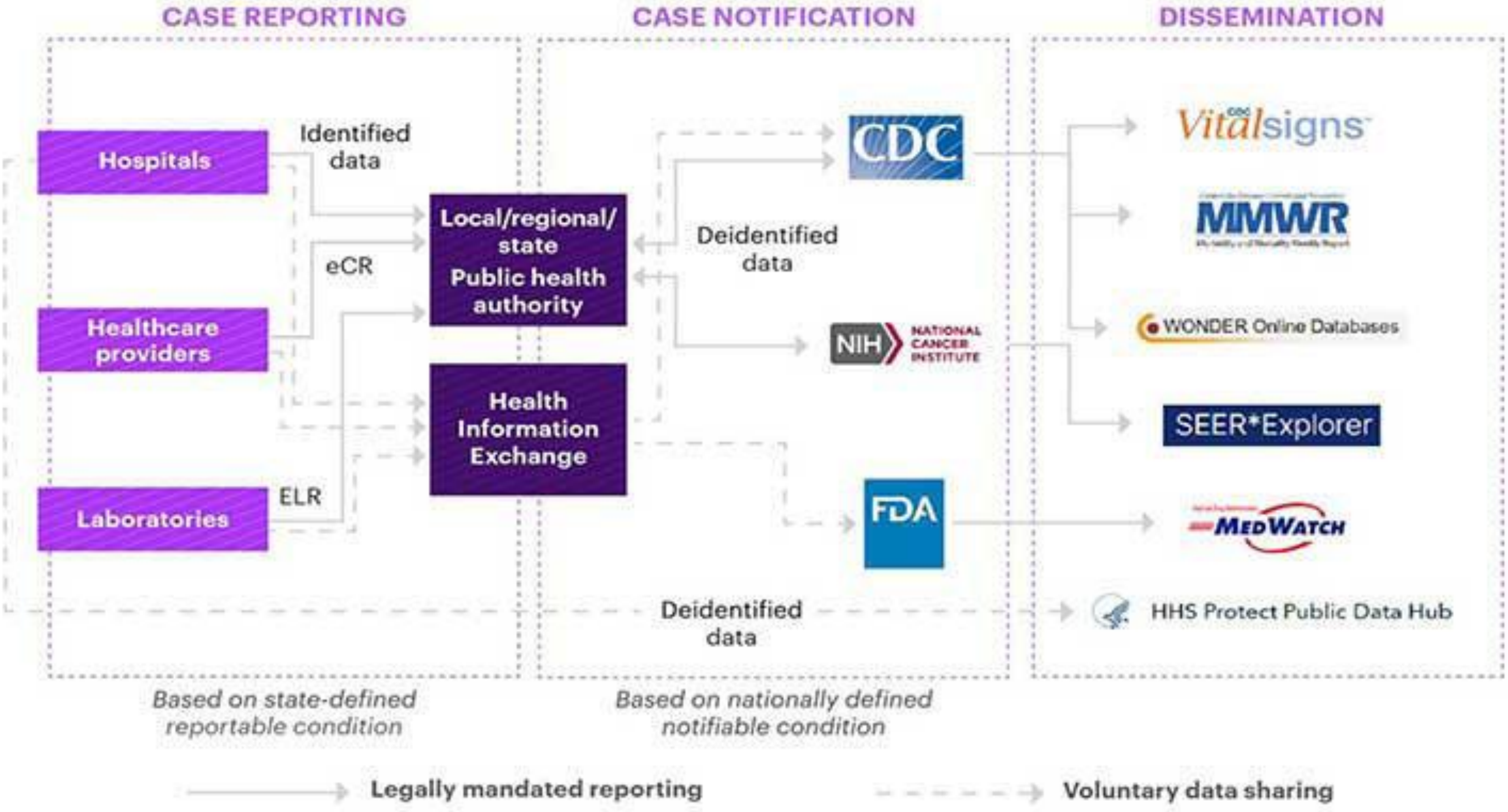

Figure 1- Sample Flow of Public Health Data [2]

Modernizing PHS has the potential to narrow gaps evident during the COVID-19 epidemic. Since the pandemic, modernizing PHS networks has become a bipartisan priority; President Trump worked with the US Digital Service to improve data exchange, and President Biden issued an executive order on his second day in office to advance public health data and analytics. [3]

2. Legal Issues

There are several legal considerations when it comes to using data that are collected and stored by a private organization for the purpose of modernizing PHS. These issues can be, but are not limited to, legal and regulatory frameworks (e.g., HIPAA and HITECH), ownership and use of data, and consent.

2A. Legal and Regulatory Frameworks

Private organizations play a key role in supporting U.S. PHS, where the legal and regulatory frameworks are complicated. Two of the most important federal laws that control the use and sharing of health information are the Health Insurance Portability and Accountability Act (HIPPA) and the Health Information Technology for Economic and Clinical Health Act (HITECH).

2AI. The Health Insurance Portability and Accountability Act of 1996 (HIPAA)

HIPPA was created in 1996 under the Clinton Administration. The act consists of 5 Titles. [4]

Title I: Protects health insurance coverage for workers and their families who change or lose their jobs and limits new health plans' ability to deny coverage due to a pre-existing condition.

Title II: Prevents Health Care Fraud and Abuse; Medical Liability Reform; Administrative Simplification that requires the establishment of national standards for electronic health care transactions and national identifiers for providers, employers, and health insurance plans.

Title III: Guidelines for pre-tax medical spending accounts provides changes to health insurance law and deductions for medical insurance.

Title IV: Guidelines for group health plans provides modifications for health coverage.

Title V: Governs company-owned life insurance policies and makes provisions for treating people without United States Citizenship and repealed financial institution rule to interest allocation rules.

HIPAA covers all persons working in a healthcare facility or private office, students, non-patient care employees, health plans (e.g., insurance companies), billing companies, electronic medical record (EMR) companies. [4] Under HIPAA, any health information that includes an identifier that connects a particular patient to that information (e.g., name, social security number, phone number, email address, or street address) is protected. [4]

2AII. The Health Information Technology for Economic and Clinical Health (HITECH)

The American Recovery and Reinvestment Act of 2009 included the Health Information Technology for Economic and Clinical Health (HITECH) Act, which advocates for an unprecedented federal investment in health information technology (IT). [5] The HITECH Act promotes health IT adoption and use in five crucial ways. [5]

- **Empowerment of the office of the National Coordinator -** Office of the National Coordinator for Health Information Technology (ONCHIT) developed a thorough strategic plan and led public and private health IT standardization and harmonization efforts. This provision does not mandate specific health IT or a federal takeover. It's an insurance policy to ensure providers have a complete health IT system if private-sector health IT developers don't comply with HITECH's mostly voluntary provisions.

- **Establishment of Unified Standards and Certification -** Aligning standards for digital health information collection, clinical use, and electronic sharing was ONCHIT's top priority. Congress was frustrated by the lack of information sharing between providers due to different technology standards used by developers. ONCHIT addresses issues standards with the Standards Committee to help the federal government gather and electronically exchange healthcare data.
- **Building the Infrastructure for Health Information Technology -** Congress allocated $2 billion to fund health IT deployment and data exchange projects.
- **Protection of Privacy and Security of Health Information -** Congress recognized that expanding health IT would be meaningless if patients and providers felt their data was safer in paper charts than electronic ones. HITECH was the right time to update and improve HIPAA privacy and security rules to reflect the increased use of health IT. These actions include clarifying and strengthening patient data access and transfer rules without patient consent. The bill compels providers to notify patients if unauthorized parties access their medical records. It mandates health IT providers to give patients "audit trails" so they can see where their health records went. Finally, it raises fines for providers who violate patient privacy rules.
- **Provision of Incentives Through Medicare and Medicaid -** HITECH made doctors, hospitals, and other providers eligible for Medicare and Medicaid incentive

payments for effective use of ONCHIT- and National Institute of Standards and Technology-certified EHRs.

Although HIPAA already provided privacy and security protections, HITECH acknowledged the significance of these issues and placed a strong emphasis on funding HIPAA enforcement and education efforts as well as identifying any potential need for additional safeguards. [6]

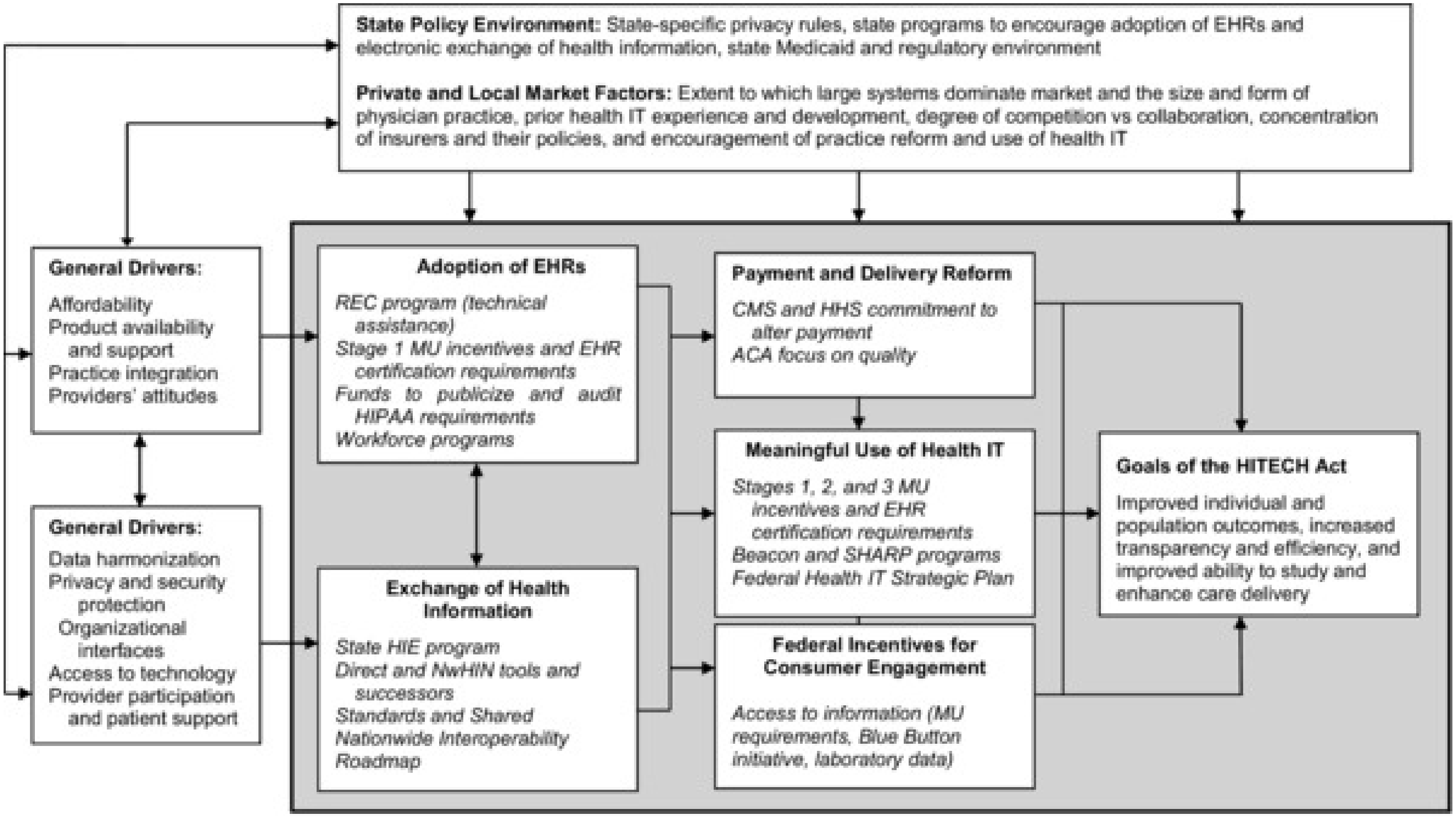

Figure 2- Framework for Global Assessment of HITECH

This image summarizes the central ideas of the HITECH Act, including the programs and policies that are included to carry out its objectives, important aspects of the environment in which it is being implemented and crucial interdependencies that will affect the HITECH Act's final success. [6]

2B. Date Ownership

When private entities are involved, the topic of data ownership and use can grow complex. The term "data ownership" defines both ownership and accountability for data; ownership entails influence and power. [7] The right to delegate these access rights to others is also included in information control. This has the right to access, create, change, package, sell, or remove data. [7] It is necessary to prevent unauthorized individuals from accessing and using the data, which could include social security numbers, medical records, and other sensitive information.

To address these issues, public organizations must establish clear policies and guidelines for data collection, use, and storage, as well as security measures to protect sensitive data from cyber security attacks and other security breaches. [8] A system for who owns health data must work around technical, economic, legal, and ethical problems while balancing the needs of different groups (e.g., data subjects, researchers, sponsors, and society as a whole). [9]

2C. Consent

The principle of informed consent, meant to ensure that health care is legal, reflects the idea of autonomy and self-determined decision-making on the part of the person who needs and wants medical and/or surgical interventions. [10] To give their informed consent, a person must be thoroughly informed about the nature and specific goals of the project, the data being gathered, and how that data will be used after they have participated. [11]

Informed consent makes it easier to gather, use, and process personal data in a way that respects study participants' ownership of that data and gives them control over it even after giving it to the study. [12]

For various reasons, informed consent is becoming more crucial when conducting research in public health. Three issues stand out: first, dealing with data means dealing with information about people, and each research participant is acknowledged to have inherent rights that should be protected; second, the data collected can be very sensitive and can have severe ramifications for the person providing it. [11] The concluding point is even more relevant when researchers from non-profit organizations, like universities, work with for-profit organizations, like many private entities.

3. Ethical Issues

There are several ethical considerations when it comes to using data collected and stored by a private organization to modernize PHS. These issues can be but are not limited to a conflict of interest, discrimination, and public trust.

3A. Conflict of Interest

Conflict of interest is when a person or group appears to be at risk of behaving with prejudice due to personal interests. [13] Conflicts of interest happen when a secondary interest, like making money or getting ahead in your career, could make a professional's decisions or actions about a primary interest wrong. [14] Conflicts of interest can negatively affect the lives of millions of people when they are present in the formulation of public policy, particularly when those policies are about health or nutrition, such as the vaccine policy, tobacco control, and studies on health. [15]

The existence of public health partnerships is dependent on the identification and management of the conflicts of interest that will inevitably arise when public and private groups collaborate. [16] Effective ways to spot and deal with conflicts are a key part of achieving the goals of public health research. [14]

3B. Discrimination

Another significant ethical issue in PHS is the possibility of discrimination based on personal health information. Discrimination can make it harder for people to get public health services and is one of the main reasons why people in minority groups have worse health than people in majority communities. [17] The identification of populations who may be at increased risk for disease or a specific stigmatized disease can be achieved through data for PHS. This information could lead to discrimination against these groups, which could hurt them in ways like limiting their access to healthcare or job opportunities.

Discrimination influences both the structural and individual levels. Structured discrimination is when large-scale factors limit the "opportunities, resources, and well-being" of less advantaged groups. [18] Individual discrimination is unfavorable interactions between people in their institutional roles (e.g., doctor and patient) or as members of the public or private sector (e.g., salesperson and customer) based on their personal qualities. (e.g., race, gender) [19]

There are many examples of discrimination based on communicable and non-communicable health conditions such as HIV, mental health, and cancer.

- **Human Immunodeficiency Virus (HIV) -** HIV is a potentially fatal condition brought on by a virus that compromises immune function and spreads through blood and sexual contact.[20] HIV-related stigma is fueled by a number of factors, such as (1) fear of infection, where people living with HIV (PLHIV) may be perceived as threatening due to the infectious nature of HIV; (2) worries about productivity and longevity; where PLHIV may be perceived as having poor prospects for employment, friendships, and romantic relationships; (3) Social norm enforcement: Since HIV risk is linked to a number of socially taboo behaviors (e.g., same-sex relationships, injecting drugs, and sex work), PLHIV are thought to be associated with these behaviors and are consequently undervalued. [20] Adolescents and young adults with HIV report a variety of stigmatizing experiences from others, such as social rejection, isolation, rumors, and inadequate healthcare, and they run the risk of internalizing stigma. [21] The effects of HIV stigma on those at risk of contracting the virus or who already have it include increased HIV risk behaviors, decreased HIV testing rates, poorer engagement, retention in HIV care, and worsened medication initiation and adherence. [20]

- **Mental health -** Mental health stigma is frequently based on the stereotypes that people with mental health issues are dangerous (unpredictable, violent), unaccountable for their mental health condition, unable to control or recover from it, and should be ashamed. [22] People with mental health issues are also frequently seen as incompetent and unable to work or live independently. [22] The common symptoms of mental health-related stigma include expected and perceived stigma, which can increase one's anxiety about admitting they have a mental health problem and possibly cause them to feel ashamed and delay getting help. [20] The stigma around mental health also has a significant impact on people's possibilities in life and their ability to reach their potential; it is linked to lower self-efficacy and self-esteem as well as reduced participation in employment and independent living. [23]
- **Cancer -** Cancer is a broad term for a variety of diseases defined by the uncontrolled growth and spread of abnormal cells. [20] Perceptions of the individual's responsibility for having the disease are crucial in stigmatizing various types of cancer. [20] For example, lung cancer is highly stigmatized because of

the idea that smoking is the primary cause, which is under the person's control. [24] The majority of individuals have negative attitudes toward smoking and smokers, which may contribute to the stigmatization of patients with lung cancer. [25] This stigmatization can have a variety of detrimental consequences. Internalization of cancer-related stigma results in lower self-esteem and poorer mental health, smaller social networks, and fewer opportunities to obtain social assistance, and higher predicted social rejection, all of which reduce the quality of life. [26]

3C. Public Trust

To support a private entity helping to modernize PHS, the public must trust that the partner will keep their personal information safe and only use it for legitimate public health reasons. Data sharing on a wide scale is essential for upgrading PHS and promises to address the health system's difficulties by getting the appropriate information to the right person at the right time by merging research and clinical care. [27] Integrated HIS help people work together by linking healthcare practice, research, and public health through social and technical systems. [27] They enable the sharing of data across sectors and support learning.[27]

Public health is for the good of everyone and is based on trust between the public and the institutions that govern them. Public health agencies should keep the highest standards possible to keep trust. [28] Five things must be in place for systems that link and collect personal administrative, medical, and biological data to be governed in a trustworthy way. [29]

- **Representativeness -** Taking into account the entire spectrum of individual and public interests
- **Accountability -** The capability to audit data use and management within an operating organization; consequences for violations.
- **Transparency -** The operations and decision-making processes are scrutinized.
- **Reflective Practice -** Regular examination of operations and data use, including fit with original intent, approvals, and consents.
- **Sustainability -** Long-term financing and administration are taken into account.

4. Amazon and AWS

Amazon.com is a world-leading online shopping platform popular in the United States; around 150.6 million mobile users worldwide access the website to buy goods and services. [30] Amazon.com has branch offices in many countries and offers a wide variety of products from A to Z, such as web services, data storage leases, and cloud computing. [30]

AWS was launched in 2006 to enable other organizations to benefit from Amazon's experience and investment in running a large-scale, distributed transactional IT infrastructure. [31] Today, AWS serves hundreds of thousands of customers worldwide and runs a global web platform. [31] AWS provides remote computing services via Amazon.com to create a cloud computing platform that replaces IT infrastructure, provides agility and instant elasticity, is open and flexible, and maintains a secure network. [1] Compared to traditional local datacenter-based solutions, cloud-based computing environments are available at a fraction of the time and effort. [1] Advanced hardware, network, and security resources are available through cloud computing to speed up analysis and reporting. [1]

5. Public-Private Partnerships in Public Health

Public-private partnerships (PPPs) are becoming increasingly important in public health because they allow the public and private sectors to work together to improve health outcomes. PPPs can combine the resources and expertise of the public and private sectors in order to achieve joint health objectives. PPP is a way for the public sector (the government and other government agencies) to use the private sector (cooperatives, private companies, charities, and nongovernmental organizations) to provide infrastructure services like water, transportation, health, education, and cloud-based software. [32]

A contract is made between the public and private sectors to share the risk, responsibility, and benefits of providing infrastructure services and ensure that the skills and resources of both sectors are working together. [33] Governments use PPPs to accomplish their aims and policies efficiently and cost-effectively. [32] Arguments in favor of PPPs include the fact that governments cannot address the enormous threats to health alone; that PPPs enhance the capacity, quality, and reach of public health services; that partnerships help to integrate health into all policies; that they improve self-regulation; and, finally, that PPPs promote sustainable business models that allow breakthroughs in more healthful product design and content. [34]

Public-private partnerships (PPPs) in the health sector have been criticized because they can lead to conflicts of interest and could weaken rules meant to protect the health of the population. [34] Collaboration in health promotion can provide enterprises that make disease-related products legitimacy and credibility, but it can lead to potential institutional corruption. [34]

CDC has an ethical obligation to check out any possible public-private partnerships and has standardized processes and practices for doing this. [35] The Advisory Committee to the Director (ACD), which was made up of people from academia, healthcare, non-profit organizations, and private industry, looked at the policies and practices that were already in place and suggested changes that should be made. [35] The ACD outlined four broad recommendations that should shape public-sector collaborations with private industry: [35]

- Promote transparency, all policies, procedures, and guidelines regulating collaborations with private industry should be made public should involve making public information about all projects sponsored by private firms and how the relationship supports agency priorities and the core mission.
- Public advantages should be apparent and measurable and outweigh the dangers should not undermine public trust in the agency or cause a reputational risk.
- All agency staff members should be informed about the partnership policies. Decision-making should be evaluated using a complete review process led by specific criteria and systematically examining agency priorities, risks, and rewards.

- Public agencies should consider whether private businesses should be barred from participating in partnerships if their activities clash with the public agency's objective, exercise undue influence, or utilize the public agency to market their products or services.

Chapter 4: Discussion

This literature review thoroughly examined many of the legal and ethical issues when a private entity is used to modernize the U.S. PHS.

Implications for Public Health

As defined by the Institute of Health in 1988: "Public health is what we, as a society, do collectively to assure the conditions in which people can be healthy." [36] Public health surveillance (PHS) strategies have failed to assure the general public's safety. The need for modernizing PHS is more significant than ever. The purposed Data-entry Once, One Health, Integrated Disease Surveillance and Response (IDSR) Health Information System (HIS) to modernize U.S. PHS supported by a private entity may be the answer to saving countless lives and assuring the conditions in which people can be healthy.

Limitations of Literature Review

When it comes to PHS, the recent pandemic has sparked widespread outrage and mistrust. Researchers must keep looking at how people feel about digital data being used for public health and how willing they are to give it. This is because people are becoming less trusting of science, spreading false information, and using ethical methods in studies is essential. [37] The attitude toward positive and negative concerns continues to alter based on a variety of topics ranging from legal and ethical issues to political and health literacy. With so many variables and moving parts, it's getting harder and harder to figure out what the public thinks about PHS modernization.

Chapter 5: Conclusion

Incorporating private entities and their products into modernizing PHS can significantly improve PHS and management efficiency and efficacy. However, it creates significant legal and ethical issues that must be adequately explored and addressed. We must ensure that this new data effort helps public health while safeguarding individuals' rights and welfares by carefully evaluating and addressing the legal and ethical problems.

Chapter 6: Recommendations

To address the legal and ethical issues to modernizing PHS supported by a private entity, the following recommendations are presented:

- **Legal**
    - Ensure all legal and regulatory frameworks, including HIPAA and HITECH, are followed to ensure the privacy and security of individuals' health information.
    - Establish explicit policies for data usage and disclosure, as well as explicit data ownership and management.
    - Ensure all individuals who supply data do so with their informed consent.
- **Ethical**
    - Address conflicts of interest and prioritize public health objectives over potential financial or commercial interests.
    - Make certain that data is not used in a discriminatory manner.
    - Confirm that the five prerequisites for trustworthy governance of systems that link and collect personal administrative, medical, and biological data are met.
- **PPP**
    - Establish a clear-cut contract with the private entity that ensures that the rights and safety of individuals are protected and not violated.

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