HEALTH INFORMATION TECHNOLOGY AND SURVEILLANCE FRAMEWORK

A guide for planning and development
at National and State levels

FEDERATED STATES OF MICRONESIA

DEPARTMENT OF HEALTH AND SOCIAL AFFAIRS

PALIKIR, FM 96941

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Acronyms

CBO   community-based organization

DHS   demographic and health survey

DHSA   Department of Health and Social Affairs (National Government)

EHR   electronic health records

FSM   Federated States of Micronesia

HIS   health information system

HMN   Health Metrics Network

HRMIS   human resources management information system

ICT   information and communication technology

IT   information technology

KPI   key performance indicator

NHN   national health number

PAS   patient administration system

PHIN   Pacific Health Information Network

PICTs   Pacific Island countries and territories

POLHN   Pacific Open Learning Health Network

RCT   randomized control trial

SDG   Sustainable Development Goal

SIDS   small island developing state(s)

SPC   Secretariat of the Pacific Community

STEPS   STEPwise approach to surveillance

UHC   universal health coverage

WHO   World Health Organization

WPRO   World Health Organization Western Pacific Regional Office

YRBSS   Youth Risk Behavior Surveillance System

Executive Summary

The 2014 Health Summit of the Federated States of Micronesia (FSM), convened at Palikir, Pohnpei from August 18-20, 2014, aimed to unify the numerous nation- and state-level policies, directives, initiatives, commitments, and programs to improve, guide, and sustain health development. One priority area of the strategic framework that came out of the Health Summit was Health Information and Surveillance, with the overarching goal of improving the availability, accessibility, quality, and use of health information for evidence-based decision-making across the health sector. This goal was broken down into seven areas of strategic action:

1. Develop and implement national- and state-level strategic plans.
2. Evaluate and harmonize all health surveillance information systems.
3. Migrate to electronic health records systems.
4. Strengthen IT infrastructure.
5. Secure political engagement and commitment at the national, state, and local levels.
6. Establish event-based surveillance at the state level.
7. Improve completeness, timeliness, and accuracy of health data.

The purpose of this document is to serve as a guide for the Department of Health and Social Affairs (DHSA) in furthering its vision and mission in health information technology and surveillance, and to be used by the Department to support its efforts in securing donor partners and funding. Additionally, having access to estimates that can give decision-makers a better picture of what's going on inside the country can pave the way to better allocation of resources.
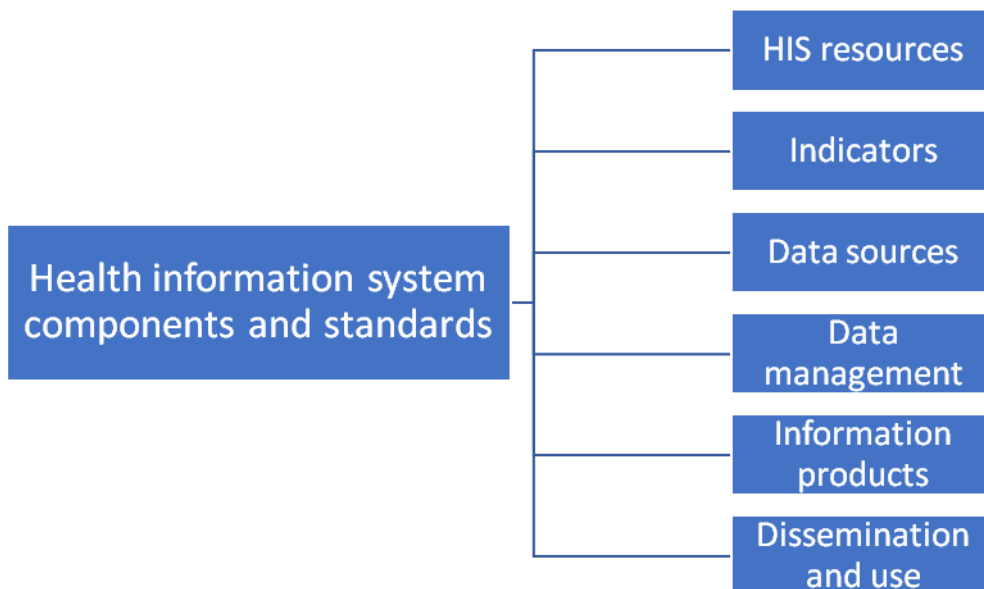
Introduction

The FSM region encompasses diverse geography, populations, cultures, economies, and politics. It includes four states, with an estimated population of 105,544 people (World Bank, 2017). The FSM is separated into four regions of the four states: Yap (west), Chuuk, Pohnpei, and Kosrae (east), each with ethnic, linguistic, and cultural differences.
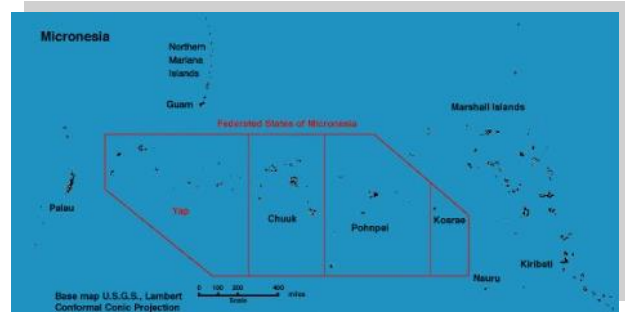
Health outcomes in the FSM vary with subregion. Infectious diseases continue as a major health concern for some subregions, while urbanization and changes in lifestyle and diet have changed the epidemiology in the country. These factors have caused a rapid increase in noncommunicable diseases (NCDs).

There is little published material on health information systems (HIS) in the Pacific region, but a push since 2009 has seen a noticeable increase. For recent decades and persisting today, it is often thought that information from many Pacific Island countries and territories (PICTs) is incomplete, unreliable, obsolete, and of poor quality (Finau 1994). To address these misconceptions and strive to close this research gap, in 2009 the Health Information Systems Knowledge Hub of the University of Queensland hosted the meeting of the Pacific Health Information Network (PHIN) and the Pacific Health Information Systems Development Forum ('the Forum'). The FSM was represented as a partner country at the PHIN meeting and the Forum.

These meetings were designed to bring together regional country stakeholders and global health information systems leaders to engage in discussions regarding the latest knowledge developments in health information systems. Both meetings provided the opportunity for knowledge and experience to be shared among a broad community of interested stakeholders, global expertise, and representatives from across Pacific Island countries and territories.

HIS Components and Standards

The Health Metrics Network (HMN) divides health information systems conceptually into six components in their *Framework and Standards for Country Health Information Systems* (WHO, 2008). There is clear value in defining what constitutes a health information system and how its components interact with each other to produce better information for better decisions and better health. In addition to its six components, a health information system can be further subdivided into its *inputs*, *processes*, and *outputs*. Inputs refer to resources, while processes touch on how

indicators and data sources are selected and data is collected and managed. Outputs deal with the production, dissemination, and use of information. These components are used to focus country strategic planning, as well as to inform about current practice and challenges within the FSM health information system. Accordingly, the six components of a health information system are:

Inputs
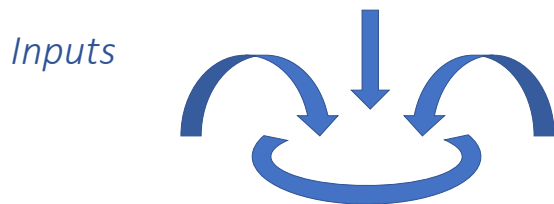
Health information system resources

These include the legislative, regulatory, and planning frameworks required to ensure a fully functioning health information system, and the resources that are prerequisites for such a system to be functional. Such resources involve personnel, financing, logistics support, information and communications technology (ICT), and coordinating mechanisms within and between the six components.

Health information system resources are the input component of a given health information system. In the FSM, infrastructure and workforce are two of the main HIS resources.

Infrastructure resources consist of physical infrastructure such as internet and computers, as well as email, mobile phones, and portable devices through which health professionals conduct their activities. A fully integrated, web-connected database is also an important resource and one that DHSA recognizes as a need. The Department is currently in the process of transitioning towards a web-connected database.

A second important resource for a well-functioning HIS is a strong workforce.

Processes

Indicators

A core set of indicators and related targets for the three domains of health information is the basis for a health information system plan and strategy. Indicators need to encompass determinants of health; health system inputs, outputs, and outcomes; and health status.

Technical staff from FSM-DHSA and each state Department of Health held a workshop for Health Data Improvement and Strengthening on Pohnpei island from February 22-23, 2017. During this workshop, participants agreed that reliable and accurate reporting of health information to document health status should be a core function of their national and state governments. Previous reports have cited that the government's ability to report accurate and verifiable health indicators is inadequate, and the workshop aimed to address this.

Participants concluded that the 14 health indicators that had been used since 2004 were outdated. They used the workshop as an opportunity to review the existing key performance indicators (KPIs) for health, in addition to reviewing methods and means used in their collection for further improvement. The workshop also aimed to increase participants' knowledge, understanding, and appreciation of the KPIs, along with brainstorming ways to minimize inconsistencies and errors in the reporting process. An ongoing goal at the adjournment of the workshop was to automate the collection and reporting of the KPIs where possible across the FSM.

In conclusion of the workshop, participants decided upon 27 KPIs for health, which can be found in Appendix D.

Objectives to be considered in future HIS strategic planning include:

- Update KPIs and identify/develop definitions and methods for each

- Identify staffing and resource needs for KPI monitoring, and identify ways to minimize reporting burden, assure accuracy and consistency of measurement, and maximize impact of KPI monitoring

- Identify ways to improve the reporting and monitoring of KPIs

- Review current reporting for TB, leprosy, and diabetes initiatives and identify any needs for upgrading reporting system

Outputs:

- A set of KPIs with clear definitions, methods for collection, and source of data (Data Dictionary)

- A set of recommendations regarding KPI selection, assuring accurate and consistent reporting, and maximizing impact of performance

Key considerations for the panel include but are not limited to: Who will lead preparation of the national KPI profile each year? Who will do technical data work at each state each year? How do we protect data integrity and consistency year-to-year? What resources are needed in relation to financing and staffing? How do we maximize impact and use of KPIs? Reaching consensus and endorsement will be critical.

All indicators are flawed, whether qualitative or quantitative. What matters is not finding the perfect indicator, but settling upon a *consistent and intelligent* method of assessing our output results, and then tracking our trajectory with rigor. What do we mean by great performance? Have we established a baseline? Are we improving? If not, why not? How can we improve even faster toward our audacious goal?

Any journey from good to great requires relentlessly adhering to these input variables, rigorously tracking our trajectory on the output variables, and then driving ourselves to even higher levels of performance and impact.

Data sources

Data sources can be divided into two main categories; (1) population-based approaches (censuses, civil registration, and population surveys) and (2) institution-based data (individual records, service records, and resource records). A basic set of standards for each source and strategic elements in achieving these standards are important. It should be noted that a number of other data-collection approaches and sources do not fit neatly into either of the above main categories but can provide important information that may not be available elsewhere. These include occasional health surveys, research, and information produced by community-based organizations (CBOs).

Data management

Data management covers all aspects of data handling from collection, storage, quality-assurance, and flow, to processing, compilation, and analysis. Specific requirements for periodicity and timeliness are defined where critical – as in the case of disease surveillance.

Among other things, data management involves creating data collection tools and creating databases for storage of information that is collected. It also means ensuring that the data that is stored can be preserved for long-term use and is in a format that's usable to a wider research community. The data should live 50, even 100 years into the future. The information that DHSA is developing right now should be used to support the evidence that it generates, and this information can and should be looked back at in the many years to come.

Data comes from quite a wide array of information sources, including being generated by diagnostic laboratories (i.e. tuberculosis, HIV, etc.) and epidemiological surveys.

DHSA acknowledges that it faces challenges regarding data management. However, with recent developments in technology, we have new tools that are being developed to promote better collection of data and production of higher quality of data.

DHSA is committed to ensuring the use of internationally defined standards in the way we collect, in the way we define, and in the way we store our data. This enables our data to be

useable by a wider community, and to be beneficial to and able to be applied into different settings.

Outputs
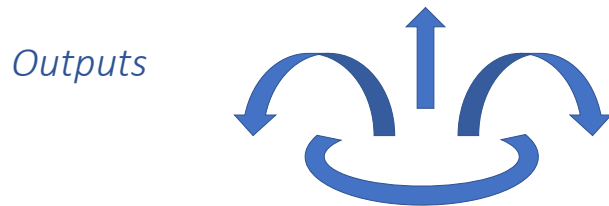
Information products

Data must be transformed into information that will become the basis for evidence and knowledge to shape health action.

Finally, the rapidly emerging area of social media for health care should be explored further. Despite cellular subscriptions being relatively low in the FSM, it can be expected that smartphone/featurephone ownership is higher, and social media use is only growing as more villages, islands, and regions come online. It would be prudent to increase information dissemination through the development of DHSA social media channels.

Dissemination and use

The value of health information can be enhanced by making it readily accessible to decision-makers (giving due attention to behavioral and organizational constraints) and by providing incentives for information use.

For a health information system to function, various policy, administrative, organizational, and financial prerequisites must be in place. Supportive legislative and regulatory environments are needed to enable confidentiality, security, ownership, sharing, retention, and destruction of data. Investment from domestic and international sources is required to strengthen ICTand provide human resources to run these systems. Expertise and leadership at national and state levels must also be provided to enable the monitoring of data quality and use. And there must be infrastructure and policies in place to transfer information between producers and users both inside and outside the health system.

Limited national resources and capacities affect how far the FSM and its states can apply the full standards, and how this may be achieved. In the four FSM states, standards did not previously exist, and they are likely to evolve over time as states adapt, use, and learn from both the FSM Framework and the HMN Framework.

Health Information Systems Agenda

There are increasingly rigorous international and national demands on health information systems. Health information systems are important for a well-functioning health system, especially due to increased accountability for resource allocation and the need for measuring health outcomes. For donors and decision-makers to invest financially in health information systems, it is becoming more important that performance requirements such as quality, coverage, and efficiency are met.

However, there are many well-known complexities of health information system activities in island settings like the FSM. They are systematic in nature, with no easy 'quick fixes' such as through rapid introduction of information technologies and communication.

Data integration and reconciliation issues are prominent and not made any easier by the proliferation of new health partnerships and alliances, both disease-focused and information focused, as well as the global reporting of Sustainable Development Goal (SDG) indicators. The FSM needs to be empowered to take ownership of its own health information and to lead state strategies and action plans to address such issues at a more local level. Donors should align their reporting requirements with FSM health information collections and plans.

Human resources for the national health information system are vital, and there is a need to build on existing capacities for data collection and management. In particular, DHSA emphasizes the critical need for developing skills in data evaluation, analysis, interpretation, and reconciliation from different sources. Like many countries in the Pacific, these skills in lacking in the FSM.

A health information system is vital not only for managing acute diseases but also chronic conditions. With the rapid epidemiological transition in the FSM from acute to chronic, as well as the 'double burden', there is a great need to address the long-term implications for the health system. Hence, systems need to value longitudinal patient data and institution-based data more highly and reward data collectors, managers, archivists, and analysts for their efforts.

Health information systems are expected to be fit-for-purpose to meet multiple users' needs, so they must be astutely designed. They serve multiple purposes from the perspectives of patients, providers, program managers, communities, civil societies, and decision-makers. A health information system must inform all dimensions of a health system's performance: quality, coverage, and efficiency. And it must provide this information in a timely way. An additional expectation is that the health information system will be the basis for research and knowledge generation.

There are clear reasons why FSM should be spending money on collecting these data as opposed to just providing services. Having better information from data can help with planning of services and allocation of resources. Time can also be saved, and there's a financial advantage there. Ultimately, data is key for service delivery and how we plan our health services anywhere

in the FSM. Improvements in data mean improvements in service delivery, and that means saving lives and helping people live healthier lives.

Improving Data Integration and Sharing

The WHO Western Pacific Regional Office (WPRO) defines health information system integration as 'the process of combining different components of health information systems so that they function in a more coordinated and unified manner,' (WPRO, 2006). Integration can take place at various levels of the health information system, including:

- **contents**, including indicators and information
- **data management**, using information technology to create a central repository
- **data analysis and quality assurance**, using standardized analytical and statistical techniques
- **organizational support**, including training and capacity building
- **data sharing and dissemination**, using visual analytics
- **donor inputs**, including resource sharing.

Data integration is the effort to link independent data elements or different data sources with different data types or storage mediums to create new information. In involves all aspects of data handling from collection, storage, and quality assurance to processing, compilation, and analysis. The ideal of 'perfect data' is largely unachievable because of inherent limitations in all data collection methods. In general, the majority ofpotential for data omission and for transcription and computational errors exists at the primary collection source (e.g. dispensary or clinic level in the FSM). As a result, data reported by health facilities often have quality issues, particularly bias, missing values, and computation errors. Therefore, data quality needs to be assessed, including adjustment and reconciliation of data from different sources so that the data is reliable for use for planning and reporting progress on key performance indicators.

eHealth Development

eHealth can support universal health coverage (UHC) in the FSM. It will be important to build eHealth foundations through policy development, funding approaches, and capacity building in eHealth through the training of students and professionals. Specific eHealth applications include mHealth, telehealth, electronic health records (EHR) systems, and eLearning, and they can all contribute int different ways to the goals of UHC.

mHealth

This refers to the use of mobile to promote health. In the FSM subscribers to mobile services has increased over the years. We have seen some health messages being promoted through this medium, but not enough. In some countries, there is evidence on how healthcare workers have managed to reach high-risk or target individuals to remind them about their appointments and other health-related services.

FSM needs to explore the use of the mHealth technology to promote health where subscribers to this service is available.

Telehealth

Telehealth refers to providing health service through distance so tools such as telephone, Internet application or other store-and-forward type of technology need to be explored. In the outer islands, having a two-way radio communication where Internet is still not predominantly available is still used.

In addition, linking up to medical specialists abroad (outside the FSM) through the Internet will be explored and encouraged.

Electronic health records systems

Of interest is the extent to which legal frameworks protect patient privacy in EHRs as the FSM health care system moves towards delivering safer, more efficient, and more accessible health care.

eLearning

Recent years have seen the emergence of multiple eLearning outlets that the DHSA can take advantage of to increase capacity of its staff, as well as aid the greater health sector workforce in the transition to more eHealth applications such as EHR systems.One such outlet is the Pacific Open Learning Health Net (POLHN), developed by WHO and Pacific Ministries of Health, which provides free online learning opportunities to health workers in the Pacific. DHSA can

make continuing professional development freely accessible to all health sector workersthrough the use ofrelevant, effective, and quality eLearning like that offered by POLHN.

Capturing Data to Improve Health

Data can be used to address a range of challenges. As it is increasingly important to rely on data to inform decisions, DHSA can use the massive amount of data that it is collecting to extract new knowledge and inform decision-making. By taking both the methodological rigor and the enormous number of advances in areas such as computation and data visualizationand bringing this to bear with the top scientific questions facing our island communities, the Department can really impact the way that islanders live.In the general area of public health, FSM will now be able to rely on data to measure all kinds of variables.

Dr. Francesca Dominici and David Parkes, co-directors of Harvard University's Data Science Initiative, discussed how having access to the right data can make the problem we are trying to solve look completely different (Harvard Chan, 2017). Data can be used to inform policy in several ways. As policy and important changes in policy should be informed by science, data has a natural role to play. DHSA recognizes the importance of keeping the bar very high in terms of producing and using only the best possible data, regardless of the context. As such, the Department aims to build consistency in taking the most reliable source of dataand using what the data says to inform policymaking.

DHSA seeks to harness data to improve decision-making, recognizing that the need for causal modeling is very important. Data means new knowledge and information, and not confusion or absence of information.We are now in an era where everything is becoming more personalized, and data will give DHSA new insight into how to make health care delivery more personal.

In general, society would benefit greatly from a better understanding of how information flows around social networks, how we form our beliefs about things, how we make decisions, how our opinions are influenced. These are things that we don't fully understand and that clearly have a large impact on our society.

More broadly, data can give DHSA and other FSM National and State departments new insight into what the right policy instruments might be to make our island cities function in a better way. Economic models are too simplistic in that they don't model decision-making at the household level; instead, they kind of model everybody in a block making one type of decision and thus they aren't at the level of detail that is needed. Data, on the other hand, can help us understand

complicated socio-economic questions. With the right technology systems, we can find a better way to understand that, thus improving decision-making at both the individual level and the level of cities and governments. It's very challenging, but it is a goal of DHSA to be able to get towards that.
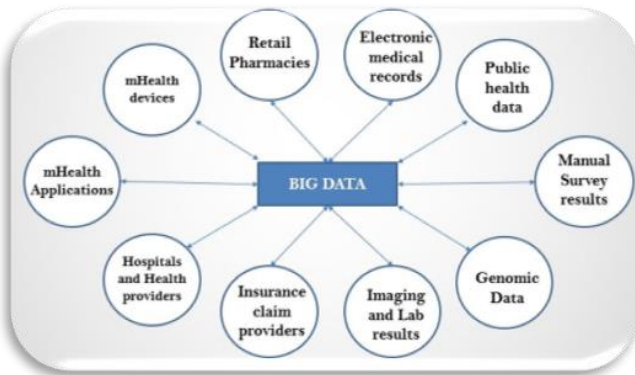
Big Data and Public Health

This section continues to expand on the importance of a data-driven approach to public health, particularly as it relates to research conducted in the region.

In an ideal world, we can answer questions about health policy and interventions through randomized control trials (RCTs), the gold standard of scientific research. But in many cases, conducting RCTs is not possible; it could be too expensive, too difficult to enroll the right number of people, or the study itself may be unethical.

That's where big data comes in; researchers are now able to harness vast amounts of existing information on patients, such as in various databases, to replicate RCTs, in a sense. It's an approach with great promise for the public health sector, but also one with potential downsides if the research isn't conducted properly.

Miguel Hernán, the Kolokotrones Professor of Biostatistics and Epidemiology at the Harvard T.H. Chan School of Public Health, is a leading expert in the field of causal inference, which includes comparative effectiveness research, to guide policy and clinical decisions. He discusses how researchers are using big data to answer important questions about health, and the safeguards that need to be in place to avoid misleading results (Harvard Chan, 2018).

Big data refers to large databases where patients' interactions with the healthcare system are stored. Every time somebody goes to the doctor, receives a diagnosis, or starts a new treatment, the information goes into a database. When you put all FSM patients together, that is a database with millions of data points that can be used for research purposes. In building these databases through the transition to EHR systems, it is important for DHSA to have strict protocols in place to prevent any leaks of personal information.

The field of big data has grown rapidly over the last decade or so. Health professionals and researchers started to use big databases in the 1970s, especially in high-income settings. In the FSM, some Department units have been using big databases for many years, including the immunizations unit, but most programs have not had electronic database storage.

Causal inference studies are used to try to learn what works and what doesn't work to improve health using big data. For example, a causal inference study may ask, "How much do screening colonoscopies lower the risk for cancer?" In the past, researchers had very little data to answer these questions. For each question, researchers had to recruit participants and collect data, which meant that studies were relatively small. However, in the last couple decades, with the emergent availability of these big databases, researchers can now ask these questions and try to answer them in a more efficient way, and at a fraction of the cost.

Big data allows researchers to measure the effectiveness of interventions without the costliness of conducting an RCT. In low-resource, research-starved areas like FSM, this is crucial.

The idea of a randomized trial is that researchers randomly assign people to two different treatments, then compare the outcomes between the two groups. Because the treatment assignment happened by chance, any difference between the groups would have to be due to the treatment they are receiving. This is the best possible way of making casual inferences (Harvard Chan, 2018).

In the real world, however, there are many practical difficulties to carrying out randomized trials. Some trials would be so expensive to conduct that researchers cannot even consider them. Others would not be ethical to conduct. Other times yet, researchers are interested in the long-term effects of treatments, maybe after using them for 10 or more years, and a randomized trial simply would not be practical.

Thus, as much as researchers love randomized trials, in many cases, they are not going to be able to conduct them. In those cases, researchers' best chance to learn what works is to use big databases. Even when researchers can conduct randomized trials, they will have to wait three to five years before they know the results of the trials. In the meantime, policy and clinical decisions must still be made. For those decisions, *some* information is needed, which will come from big databases.

In a sense, researchers are taking data that is out there and then modeling what has already happened in the real world, then drawing conclusions from that. By using data that has already happened, researchers can try to emulate a randomized trial that they would like to conduct, but that they cannot.

The benefits of being formal about causal inference in this way (being very precise about the randomized trial that we would like to emulate) is that the approach results in fewer mistakes.

To an extent, researchers are currently at the mercy of the data available from FSM. If the data on a typical dimension or variable is not available, researchers may not be able to proceed with their study. There are people who want to do this type of research, but more often than not, the data doesn't yet exist. This is one of the first decisions that all researchers have to make; they may want to answer certain important questions, so they look at the available data. Sometimes, researchers just have to decide that there is not enough available data in order to provide accurate answers to their questions.

Moving forward, the ideal scenario for DHSA is to aid those conducting observational research using the Department's big databases, and to use this research to influence and guide policymaking. Then, down the line when RCTs are more practical, those can be conducted to validate or invalidate what the original study concluded. In the absence of randomized trials, it is better to make decisions based on the limited information that we can obtain from big data, rather than making decisions based on no information at all.

Health Informatics

Health informatics is about the use of information technology (IT) in healthcare. In high-income settings like the United Kingdom and the United States, IT has been used in hospitals and clinics for quite a long time, since about the 1970s and 80s. Recent research, however, has been looking at the use of IT in healthcare in low-resource settings like the Federated States of Micronesia (FSM).
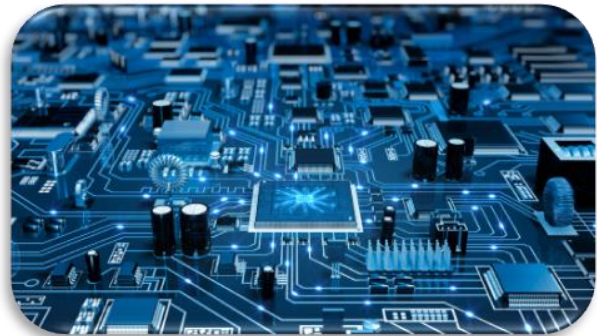
In high-resource settings, where the technology has been in place for quite a while, health professionals are now starting to use the data that's stored throughout their health systems as part of what's called a 'learning health system' (Oxford Global Health, 2016). The idea is that health professionals analyze the data that's stored in, for example, electronic health record systems to identify any problems with care. Health professionals then implement new solutions to address the issues, and finish by looking in the same data sources to see if the solutions have been effective. Recent research looks at how that same process of a learning health system can be applied in a low-resource setting.

DHSA is currently in the process of implementing electronic health records systems, while simultaneously upgrading IT systems. As part of this process, the Department should look at doing an assessment across FSM and its states of what IT systems health facilities are currently using and what they are planning to use in the future. In the past, low-resource settings like FSM have faced issues of intermittent electricity, problems with broadband connectivity, or just a simple absence of these technologies even being possible, as is the case in remote atolls.

IT systems in the FSM are quite fluid right now, with states seeing recent or upcoming upgrades in IT infrastructure and capabilities. The connection, for example, of a new fiber optic cable to Chuuk, the nation's most populous state, will dramatically increase the state's online capacity, and the implications for economic and social development are tremendous. The Chuuk health sector stands to gain, particularly as DHSA implements and establishes EHR systems. The potential for the successful transition to EHR systems in Chuuk health facilities, for example, has a much higher ceilingafter the activation of the fiber optic cable.

However, low-resource settings have also found some quite innovative solutions to those issues. Instead of investing a lot of money in creating new electricity supplies, doctors and researchers are using mobile technology, which has long battery life and can connect to the Internet over the mobile phone network. While not all remote atolls in FSM have mobile phone network connectivity, the potential in the future is great. Delivering services through mobile devices instead of traditional face-to-face meetings can reach more people at a much lower cost (Oxford Global Health, 2016).

The growth of open-source software in healthcare is another promising trend over the last five to 10 years. Despite whatever specific purpose that software has been developed for, because it's open-source, it can be taken up by other groups and developed further. Ultimately, DHSA aims to see that kind of software put into hospitals and community health centers, where it can be useful in building the learning health system.

The learning health system idea has huge potential, especially in low-resource settings like FSM. Despite recent progress, still there are many problems with chronic care, among others, and it results in a lot of premature death and disability. DHSA knows that if it can implement this idea of a continuously learning system, where doctors and hospital administrators can examine the data they're collecting and then implement local solutions based on the problems that they've identified, then that could make a big impact on how healthcare is delivered.

Global healthcare informatics is at a very critical stage at the moment. The IT systems are only just going into FSM, like many other low-resource settings, whereas they've been in use in high-income settings for many years now. There are certainly issues around the expense and difficulty of putting in IT systems in healthcare (especially in rural villages and remote atolls). But by translating the research that's been done internationally to low-resource settings, FSM can avoid repeating some of the mistakes of other countries.

Conclusions

A health information system needs to be recognized as an essential component of health system development in the FSM. A health information system should be valued for its ability to provide evidence for decision-making. In the FSM, there is an increasing understanding of its critical importance within a well-functioning health system to provide accountability for resource allocation and measuring health outcomes. As this recognition takes place, the FSM is being empowered to own its own health information and take the lead in initiating strategies and action plans to address persistent health information system issues.

As health information system workers and decision-makers in the FSM better define their knowledge gaps, the country can adequately address the issues and challenges perceived at the

national and state levels. Common issues and challenges for health information systems in the FSM and the greater Pacific Islands region have been raised.

Many health information system issues and challenges in the states of the FSM are similar to those identified elsewhere in the Pacific Islands region. The Pacific Islands region is unique because there is strong potential for regional solutions to collectively resolve some of these issues, especially in the areas of data standards, workforce development, and technological investments. The way forward to address these health information system issues for the FSM is to work as a collective group with other Micronesian and Pacific Island countries and territories in advocating and strengthening health information systems.

DHSA will actively partner with state governments, the private sector, regional organizations, and others to find solutions for the islanders who currently lack access to health information system services. Building on advances in IT capabilities, DHSA will deploy the best possible consumer and provider insights to help increase and sustain the equitable use of existing and future public health information system networks.While solutions will differ state by state, island by island, and community by community, they'll all focus on building health information systems from the consumers' perspective, which is critical to achieving sustained use of services, products, medicines, and overall quality health outcomes.

To achieve all of this, development assistance for health could use a boost. DHSA will actively partner with donors and governments to promote domestic and foreign resource mobilization to faster achieve our goals regarding health information systems.

Future actions should be taken that seek to assess the comparative priority and feasibility of implementing various suggestions presented from different regional actors, including the Health Information Systems Knowledge Hub. The FSM should properly determine the practicalities of implementing these suggestions. To do this, significant statistical organizational reform in the FSM, donor input, and regional consultation will be required.

The next step for the FSM Government, including DHSA, should be to undertake the process of a formal country-level HIS strategic planning. This process should involve actors from relevant sectors at the state level, so that they can take the experience back to their colleagues and begin the process themselves to create state-level HIS strategic plans. HMN has created a *Guidance for the HIS Strategic Planning Process*, which includes steps, tools, and templates for HIS systems design and strategic planning (Version 6, March 2009). Using this document to guide a national strategic planning process offers a great opportunity to cement the importance of health information in the FSM.

Acknowledgement

The Department of Health and Social Affairs extends its appreciation to Mr. Alexander Hoffman, a graduate student from University of Denver in the USA who volunteered his time as an intern with the department during the summer of 2018. Though key technical staff and leadership of the department also guided the development of this document, this document would not have been produced without the commitment and sacrifice of Mr. Hoffman. It builds on policies and development the department is currently undertaking. This document should guide the work of the department as it continues to explore how the health information technology can improve health development in the country.

Appendices

Appendix A: Common HIS strategies among PICTs

Source: *HIS Knowledge Hub – Issues and Challenges for health information systems in the Pacific, 2009*

1. **Improve data integration and sharing.**

   a. Improve sharing of data among health information system stakeholders.

   b. Clarify data ownership.

   c. Develop health information system legislation and/or regulations.

   d. Establish unique identifiers.

   e. Establish data standards.

   f. Improve use of technology to increase data sharing.

   g. Develop human resources for data management.

2. **Increase analytical skills among data producers.**

   a. Increase capacity for data analysis.

   b. Ensure communication of analysis and findings.

3. **Explore regional approaches to health information systems.**

   a. Recruit and retain a health information system workforce.

   b. Define core regional health information system competencies.

   c. Establish a Health Information Committee.

   d. Explore costs of information technology.

   e. Maintain quality of mortality coding.

4. **Strategize for advocacy for health information systems.**

   a. Advocate for health information.

   b. Engage decision-makers.

5. **Improve and increase the role of health surveys.**

   a. Link surveys to routine surveillance.

   b. Make surveys accessible to stakeholders.

6. **Improve the use of institution-based data.**

   a. Improve quality of individual records.

   b. Improve transmission of data in geographically isolated areas.

c. Improve service and resource records for decision-making.

d. Improve validity of mortality reporting.

Appendix B: Framework for an FSM health information system strategic plan

Strategy	Action(s)
1. Improve data integration, quality, and sharing	1.1 Investigate the feasibility of a national data warehouse (e.g., a system of linked databases, aligned around agreed standards of data and metadata quality, with user-friendly access)
	1.2 Implement a national standard or code of practice regarding data sharing
	1.3 Develop a core dataset for sharing of health information
	1.4 Develop, document, and disseminate data quality standards, including best practices for data collection methods
	1.5 Develop and implement a systematic, regular, and institutionalized system for the supervision, monitoring, and evaluation of data quality, covering all activities from data capture to data processing and analysis
	1.6 Conduct a regular, systematic, and institutionalized monitoring and review of the HIS, including: a. Periodic review of information requirements b. Continuous monitoring of disease surveillance systems c. Monitoring and assessment of the efficiency of the core and support components of the HIS
	1.7 Conduct a review of the role of health surveys and develop a strategic plan to identify which information should come from routine HIS and which should come from health surveys
	1.8 Clarify data ownership
	1.9 Establish unique identifiers (e.g., national health number)
2. Advocate for the recognition of and improvement to health information systems within FSM	2.1 Conduct advocacy activities to create awareness, discuss issues and elicit action for the following HIS-related areas: a. Systematic development and strengthening of the HIS at national and state levels (e.g., development of HIS master plans, strategic framework, strategic plans, policies) b. Resources sharing for HIS development and maintenance among different programs within DHSA and donor agencies c. Integration of information systems of different vertical programs within DHSA d. More rigid implementation of existing HIS-related laws and regulations e. Strengthening of the curriculum of nursing programs in relation to the generation and use of health information (including the use of ICD-10) f. Alignment of emerging HIS needs and activities with current management priorities (e.g., National Health Plan, etc.)
	2.2 Increase national dialogue on the incentives for data collection at the health system level
	2.3 Promote HIS among key non-health stakeholders (e.g., the Bureau of

	Statistics, Department of Justice/Civil Registry, Department of Finance and Administration, Department of Transportation, Communication, and Infrastructure, and private health providers)
	2.4 Promote the sharing and application of HIS-related experiential knowledge
3. Enhance institutional capacity and opportunities for the creation of professional development pathways	3.1 Develop HIS career paths a. Include HIS in a DHSA Workforce Development Plan
	3.2 Improve existing pre-service and in-service training for HIS personnel a. Implement and improve recognition and accreditation of training and prior learning
	3.3 Enroll in regional training in HIS, including (but not limited to): management, biostatistics, epidemiology, coding, medical record management, ICT
	3.4 Review the roles and functions of the Health Statistics & Information Unit and its place within the DHSA organizational structure, including defining the core challenges for managerial and technical HIS positions, and duties and responsibilities of a Chief Information Officer and HIS Unit
4. Strengthen the application of information and communication technology, including ICT infrastructure	4.1 Strengthen the capacity of information systems to transmit, access, and share health information
	4.2 Develop policy and implement a maintenance plan for various resources related to HIS including: a. Physical resources (e.g., record storage facilities) b. Replacement and upgrading of equipment, including computer hardware and software c. Human resources (e.g., retention of qualified staff) d. Data and IT standards and architecture e. Disaster management and recovery
	4.3 Conduct further research and evaluate the current sustainability of health information technology investments
	4.4 Investigate emerging data transmission technologies
	4.5 Promote the sharing of IT adaptations, modules, requirements, components, methods, etc. across states
5. Develop policies, regulations, and legislation on HIS-related issues	5.1 Establish policy to facilitate the linkage of information
	5.2 Provide/strengthen the legal basis for different HIS-related activities (e.g., vital registration system, reporting of notifiable diseases, data collection from private providers, use of electronic health records, etc.)
	5.3 Prepare and disseminate user's manuals and policies for the HIS and each of its sub-systems (e.g., hospital, public health, human resources, finance)
	5.4 Establish strict protocols to prevent any leaks of personal information
6. Secure political engagement and commitment at the national, state, and local levels	6.1 Create a high-level interagency multisectoral leadership forum, including lead institutions and actors in each key agency across health and non-health sectors at national and state levels, to guide and oversee a broad set of stakeholders toward the realization of an integrated, unified, and adequately resourced HIS
	6.2 Develop the core specifications for a health information governance structure

	6.3 Enhance leadership skills, organizational development, change and risk management of HIS
	6.4 Expand linkages with the private sector through partnerships and technical advisory groups and extend coordination at the state level
7. Establish event-based surveillance at the state level	7.1 Develop and implement innovative and scalable models for expanding event-based surveillance at the state level
8. Improve the use of institution-based data	8.1 Improve quality of individual records
	8.2 Improve transmission of data in geographically isolated areas of the country
	8.3 Improve service and resource records for decision-making
	8.4 Improve validity of mortality reporting

Appendix C: Levels and Methods of Surveillance Activities

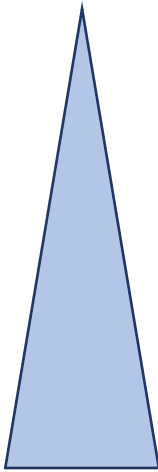### Table 1: Information needs and tools at different levels of the health-care system

Level of data collection	Quantity of data	Information needs	Information tools
Global/regional	Less	Summary indicators for global reporting, SDGs	Global/regional summary indicators
National		Summary indicators for national needs (e.g. planning)	National summary indicators
State		Indicators for state and national reporting and planning	State summary reports
Facility		Facility management, audits, planning; drug procurement	Facility registers, logbooks
Patient		Patient management	Patient charts
Household	More	Understanding population burden of disease and risk, monitoring and evaluation of CBOs	Household surveys and demographic surveillance

Table 2: Levels Where Surveillance Activities are Performed

Activities	National level (Administrative)	State level (Hospitals)	State level (CHCs)	Local level (Dispensaries)
Detection and notification of cases	No	Yes	Yes	Yes
Collection and consolidation of case data	Yes	Yes	Yes	Yes
Analysis and interpretation	Yes	Yes	No	No
Investigation of cases, confirmation of diagnosis:				
• Epidemiologist	Yes	No	No	No
• Clinician	Yes	Yes	Yes	No
• Laboratory	Yes	Yes	No	No
Feedback	Yes	Yes	Yes	Yes
Dissemination	Yes	Yes	Yes	Yes
Action	Yes	Yes	Yes	Yes

Table 3: Major Surveillance Methods

Surveillance Methods	Comments
Mandatory disease notification by health-care providers or facilities	• Require immediate public health response; or • Recognizable solely by providers
Reports by laboratories (reporting source)	• Immediate public health response may or may not be needed • Laboratory test needed for recognition or to meet case definition • Laboratory test adds relevant information • Back-up to clinician's reporting
Sentinel surveillance	• Useful for collecting detailed information on a subset of cases • Designed so findings can be generalized to a specified population • Collect limited information to recognize the onset, termination and characteristics of a particular public health problem of limited duration (such as influenza) • Used when incidence of a condition is high (e.g., diarrheal diseases)
Periodic or ongoing prevalence surveys	• To assess prevalence trends over time (e.g., HIV seroprevalence surveys, BRF surveys) • Optimal if designed to be useful to state and local public health agencies • Generate hypotheses regarding risk factors • Evaluate the effectiveness of a public health or clinical intervention
Vital records	• Surveillance of births and deaths; trends in causes of death • Key for infant and maternal mortality surveillance • May be used alone for some analyses
Secondary analysis of datasets collected for other purposes	• Places no additional burden on public health surveillance systems • Care must be taken in analysis and interpretation • Immediate public health response is not needed • Assess the public health impact or monitor trends • Measure morbidity costs due to chronic or recurrent health events • Potential data sources include hospital discharges, billing, insurance, emergency room, school/work attendance, immunization registries, work-site injury and law enforcement records

Appendix D: FSM National Health Sector Key Performance Indicators

Type	#	Key Performance Indicator (KPI)
Maternal & Child Health (MCH)	1	Infant mortality rate (per 1,000 live births)
	2	Early child mortality, <5yo (per 1,000 live births)
	3	Maternal mortality (per 100,000 live births)
	4	Teen births, 15-19yo (per 1,000 live births)
	5	Births attended by skilled personnel (per 100 live births)
	6	Immunization completeness, children 2yo
	7	Family planning services, 15-44yo (per 100 live births)
	8	Dental sealant, children 8yo
NCD Indicators	9	Youth tobacco smoking
	10	Youth alcohol use
	11	Amputation rate, lower extremity (per 100,000 population)
	12	Cancer deaths (per 100,000 population)
	13	Cardiovascular disease deaths (per 100,000 population)
	14	Diabetes deaths (per 100,000 population)
	15	Chronic lung disease deaths (per 100,000 population)
Other Major Causes of Illness	16	Suicide deaths (per 100,000 population)
	17	Road traffic deaths (per 100,000 population)
	18	Tuberculosis incidence (per 10,000 population)
	19	Leprosy prevalence (per 10,000 population)
	20	HIV incidence (per 100,000 population)
Standards, Quality, & Administration	21	Outlying health centers/dispensaries meeting quality standards
	22	Hospital & Public Health units with quality surveys and improvement plans
	23	Population to physician ratio
		Population to graduate nurse ratio
	24	Inventory: Medicines on essential list in stock
	25	Hospital equipment: Items on essential list that are functional
	26	Budget and end-of-year utilization %
		a) Compact & General Fund
		b) Health Care Fund & Health Care Revenue Fund
		c) Other large grant
	27	Population enrolled in health insurance plan

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