

Public Health Institutes of the World

**IANPHI**

Integrated Disease Surveillance Report

**DEEP DIVE SYNTHESIS REPORT**

Public Health Institutes of the World



Integrated Disease Surveillance Report

# **DEEP DIVE SYNTHESIS REPORT**

## Authors

Afifah Rahman-Shepherd (Saw Swee Hock School of Public Health, National University of Singapore, and Afifah RS Consulting), Dr. Ngozi Erundu (O'Neill Institute for National and Global Health Law, Georgetown University), Dr. Mishal Khan (London School of Hygiene and Tropical Medicine), Professor Andrew Lee (UK Health Security Agency and University of Sheffield), Dr. Bjorn Iverson (Norwegian Institute of Public Health), Ms. Sadaf Lynes (International Association of National Public Health Institutes), Dr. Anders Tegnell (Public Health Agency Sweden)

## VERSION CONTROL

Version 3.4

Date: December 14, 2022

Grant ID: INV-03787

This report is based on research funded by the Bill & Melinda Gates Foundation. The findings and conclusions contained within are those of the authors and do not necessarily reflect positions or policies of the Bill & Melinda Gates Foundation.

# TABLE OF CONTENTS

ABBREVIATIONS .....	5
1. EXECUTIVE SUMMARY .....	6
2. BACKGROUND .....	10
2.1 Introduction .....	10
2.2 Overall Project Aims and Objectives .....	10
2.3 Aims and objectives of the deep dive workstream .....	11
3. METHODOLOGY .....	13
3.1 Participants .....	13
3.2 Data Collection .....	14
3.3 Ethics .....	15
3.4 Approach to the Analysis and Synthesis of the Deep Dives .....	15
3.5 Limitations .....	17
4. RESULTS .....	18
4.1 Key Summary Findings Identified from the Country Deep Dives .....	18
4.2 Results of Synthesis Analysis .....	26
5. RECOMMENDATIONS .....	40
6. SUMMARY .....	44
7. ACKNOWLEDGEMENTS .....	48
REFERENCES .....	54
APPENDICES .....	55

## ABBREVIATIONS

BMGF	Bill & Melinda Gates Foundation
eIDSR	electronic Integrated Disease Surveillance and Response
EPI	Expanded Program on Immunization
FGD	Focus group discussion
HIC	High Income Country (World Bank classification)
HMIS	Health Management Information System
IANPHI	International Association of National Public Health Institutes
IDS	Integrated Disease Surveillance
IDSR	Integrated Disease Surveillance and Response
KII	Key informant interview
LIC	Low Income Country (World Bank classification)
LMIC	Lower Middle-Income Country (World Bank classification)
MOH	Ministry of Health
NPHI	National Public Health Institute
OHSP	One Health Surveillance Platform
PHI	Public Health Institute
UKHSA	United Kingdom Health Security Agency
WHO	World Health Organization

# 1. EXECUTIVE SUMMARY

The International Association of National Public Health Institutes (IANPHI) received funding from the Bill & Melinda Gates Foundation (BMGF) to explore the status of national surveillance systems in terms of integration of data; the role of National Public Health Institutes (NPHIs); the extent to which Integrated Disease Surveillance (IDS) systems have been developed and operationalized; and the evidence base for the effectiveness of IDS.

This global study of IDS has been divided into three projects which include:

1. A systematic scoping review of the literature
2. A survey of IANPHI members
3. Seven deep dives in three High Income Countries (HIC) and four Lower-Middle Income Countries (LMIC), undertaken between April and October 2022.

The study sought IANPHI members' understanding of IDS and the development of IDS systems globally, drawing on the literature findings to develop a framework for IDS and testing its validity against the global literature and against NPHIs' operational experience.

The international response to the COVID-19 pandemic revealed that surveillance systems globally were ill-prepared to identify and manage this public health threat. Some of the challenges were mitigated by investment into establishing systems that were needed for control and response. Morgan and colleagues discussed the challenges to disease surveillance highlighted by COVID-19 and postulated that integrating separate disease surveillance systems would help to strengthen national disease surveillance [1]. This summary of deep dives in seven countries sought to examine the extent to which the integration of disease surveillance is being operationalized, as well as the perceived benefits and challenges to greater integration.

NPHIs vary in their design and purpose, but since the COVID-19 pandemic, their role in national disease surveillance has become more evident. This report provides a synthesis of consultations, conducted with key informants from NPHIs and associated stakeholders, mostly between August and September 2022, (the deep dive in Malawi was initiated in May 2022), to understand their perspectives of current IDS systems and identify what is needed to advance IDS. The seven countries that participated in the deep dives were Canada, Malawi, Mozambique, Pakistan, Sweden, Uganda, and England. A framework based on five domains of IDS was used to identify characteristics of systems and capture common enablers and barriers to strengthening IDS from the country "deep dive" reports (appendix 2). This framework was also used in a further cross-country comparative analysis of these consultations.

## Key findings from the deep dives

None of the deep dive countries had a singular, fully established and functional integrated surveillance system. However, there were several examples in HICs of well-functioning surveillance systems integrating multiple sources of information, to varying extents, that were purpose-built and outcome oriented.

The integration of surveillance systems requires the coordination of various stakeholders, who have differing needs, and ensuring routine representation from different sectors in national surveillance activities.

Overall, there were six key issues to consider when establishing and trying to strengthen IDS systems:

1. The purpose and value of integration needs to be clarified, and integration activities should be guided by the outcomes sought.
2. Unclear or shared ownership leads to challenges and, in some countries, lack of incentives to manage a change in surveillance practices
3. Incompatibility of existing IT systems and surveillance infrastructure
4. Workforce and skills required
5. Challenging legal environment to facilitate information and data sharing within and between agencies
6. The lack of funding and investment to drive integration

Other important findings includes that the One Health approach can facilitate multisectoral and transdisciplinary collaboration, and integration of surveillance and information systems across the human health, animal health, and environment sectors.

While formal systems or mechanisms for sharing data and intelligence across agencies exist in some countries, in other countries inter-agency data sharing can be problematic. The importance of interpersonal relationships, networks, information governance and legal agreements for facilitating data sharing was highlighted. It is important to also consider integration of public and private surveillance systems, especially in countries where a substantial proportion of healthcare is through private providers

The issue of integration and interoperability of surveillance systems across borders was also raised for further consideration, given the lack of mechanisms currently to support this in many countries. Another important barrier that all countries highlighted relates to how IDS is conceptualized, both within and across different contexts, as IDS does not necessarily mean the same thing depending on context, sector, or stakeholder.

Another issue of note was the fact that HIC participants were generally unfamiliar with the term IDS or the WHO IDSR strategy. When conducting the discussions and interviews, IDS had to be paraphrased to “integration of disease surveillance” so participants could engage with the term and its concept.

## Facilitators and Barriers to IDS

Facilitators and barriers to IDS that were identified through the deep dive exercise and two group workshops that were held with the deep dive teams and are set out below under five themes.

### GOVERNANCE

#### Facilitators

- Legal agreements and mandates provide the basis for better cooperation through clarified roles and responsibilities.
- Legal frameworks and processes for reporting, access, data sharing, etc.
- Strong, committed leadership to IDS

#### Barriers

- Insufficient or shared ownership of IDS and legislation for data sharing; informal mechanisms for sharing
- Reactionary approach (“firefighting after an outbreak), rather than preventative

### FINANCING

#### Facilitators:

- Financing is increasingly targeted and available for specific actions

#### Barriers:

- Insufficient financing for sustainable functions
- Multiple external donors create challenges for coordination, access to data and ownership.
- Fragmented funding structures for developing and sustaining disease surveillance

### SYSTEM AND STRUCTURE

#### Facilitators

- Essential initial infrastructure already exists (e.g., laboratories, FETP training program, One Health working group, genome sequencing) that can be strengthened

#### Barriers

- No overarching system: in some cases, surveillance is fragmented, not interoperable, or multiple parallel systems.
- Private healthcare providers and laboratories need to be included.
- Public laboratories require skilled staff, equipment and supplies to sustain functionality
- A lot of data processing is still manual and inefficient, limited technology

### CORE FUNCTIONS

#### Facilitators

- Detect, report, analyze, investigate/confirm, respond, feedback, evaluate, preparedness was in place with various functions led by the NPHI or/and MOH and/or a center of statistics.

**Barriers:**

- Data quality and standardization issues and gaps in resources for validating, interpreting, and analyzing data, limits traceability of data points through the health system and translation of data into action.
- Country context models need to be developed looking at ground level facilitators and national level enablers.
- A one-size-fits-all approach creates barriers to implementation.
- Clarity in the lead role needs to be in place- functions can be shared if there is clarity to the organization with the key role (legal mandate, governance).

**RELATIONSHIPS BETWEEN ACTORS****Facilitators**

- Strong relationships and trust
- Strong dialogue between policymakers and public health officials
- Existing international networks and guidance (e.g., WHO HUB, Global Public Health Intelligence Network)

**Barriers**

- Lack of a shared understanding of what IDS is; disagreement with the value of IDS, as currently defined
- Lack of incentives creating low motivation or hesitancy to share data and limited awareness of its value.
- COVID-19: Distracted attention and resources; Too much data; Increased demand for data

The six recommendations below align with the facilitators and barriers explained above:

1. Clarifying the purpose of IDS through an explicit guiding definition, especially what 'integrated' means and wants to achieve as well as a country compatible definition, that sets out what is integrated, the intended purpose, as well as how integration is delivered.
2. Strengthening the workforce of surveillance; through establishing and formalizing professional networks, ensuring adequate staffing, and capacity building to provide infrastructure and tools, building skills and expertise needed to operationalize IDS.
3. Facilitating opportunities for research, evaluation and learning to strengthen expertise as well as improve and assure the quality of surveillance.
4. Ensuring that resources reflect the sustained investment needs and sufficient levels of funding that can catalyze systems integration and bolster coordination efforts needed, not only during emergencies but also for the daily operation of integrated surveillance.
5. Building an environment of data and system interoperability at every level and across sectors to serve the country's integration objectives.
6. Strengthening National Public Health Institutes and other public health entities as catalysts and system leaders for IDS. This is important to enable the synthesis of multi-sectoral data for action for decision makers and implementors.

While some additional evidence is needed to inform these recommendations and transform them into actionable steps appropriate for the different country contexts, the synthesis from this deep dive provides direction to help NPHIs steer system development to further progress IDS within their countries.

## 2. BACKGROUND

### 2.1 Introduction

Following the COVID-19 pandemic, weaknesses in disease surveillance and response in all countries have been exposed, resulting in unprecedented public and political attention to epidemic preparedness and response. Improvements in disease surveillance systems and the broader context in which they operate in are key to enabling better informed and targeted public health decision-making. One approach to strengthening disease surveillance has been the concept of IDS, which has been defined as “a combination of active and passive systems using a single infrastructure that gathers information about multiple diseases or behaviors of interest” [1]. However, there is still no universally agreed definition of IDS, and a priority should be to develop a consensus definition that can be widely used.

The increased frequency and magnitude of large outbreaks due to meningitis, cholera, yellow fever and measles in Africa led the World Health Organization (WHO) African Region in 1998 to devise and adopt a strategy called the Integrated Disease Surveillance strategy [2]. The aim of the IDS strategy was to support countries to improve their disease surveillance and response capabilities so that they could detect and timely respond to communicable disease threats. In 2000 the WHO approach to IDS in Africa was renamed Integrated Disease Surveillance and Response (IDSR) to emphasize the essential link between surveillance and response. According to the WHO, the IDSR strategy focuses on the provision of comprehensive public health surveillance and response systems for priority diseases, conditions, and events at all levels of health systems.<sup>1</sup>

Part of the IDS strategy is to make explicit the skills, activities and resources needed at each level of the health system to operate all functions of surveillance. The aims are to make surveillance systems from different sectors, including laboratory data, more usable and to help public health managers and decision-makers improve detection and response to the leading causes of illness, death, and disability. However, operationalizing IDS has proven to be challenging, including consolidating the role of NPHIs.

### 2.2 Overall Project Aims and Objectives

The IANPHI IDS project, funded by BMGF and undertaken over eight months, pulled together the current understanding and development of IDS systems globally, incorporating the lessons learned from the COVID-19 pandemic. The project comprised of three workstreams:

---

<sup>1</sup> For the purposes of this report, the terms IDS and IDSR will be used synonymously to refer to the IDS/R concept and approach.

1. To undertake a systematic scoping review to explore the current state of knowledge, definitions, and characteristics of IDS globally, and assess how these have evolved over time. Drawing on the findings of the review to develop and test a conceptual framework, that includes the core principles of IDS as set out by Morgan and colleagues<sup>5</sup> that will inform other elements of the study.
2. To survey IANPHI members to develop a clear understanding of the current state of IDS across the IANPHI network, mapping variations in definitions and approach to IDS, and collecting and collating case studies on how IDS has been developed and is managed.
3. To conduct a focused “deep dive” study on a small number of LMICs and HICs (Canada, England, Malawi, Mozambique, Pakistan, Sweden, Uganda) to study the state of IDS in those countries, including challenges and barriers to implementation, as well as identifying opportunities for development.

In addition, there will be reflections on the similarities, alignment and variations with the complementary projects on IDS conducted by Resolve To Save Lives (RTSL) and Robert Koch Institute (RKI), both of whom are separately funded by BMGF.

### **2.3 Aims and objectives of the deep dive workstream**

The deep dives workstream involved seven NPHIs in Africa, Asia, Europe, and North America, and was conducted between July and October 2022, with the exception of Malawi which was initiated in May 2022). The participating NPHIs and basic demographic and health systems information for each country are detailed in Table 1. The aims of the deep dives were to understand how IDS is conceptualized and operationalized; how context has shaped the current provision of IDS; and the perceived strengths, weaknesses, and challenges to future evolution of IDS. The objectives of the deep dives were to identify and generate primary data to:

1. Explore participants’ understanding of current surveillance systems and the extent to which an IDS system has been developed in the country
2. Understand types of surveillance programs in the country, including how they are managed, funded, coordinated and the extent to which they are integrated at national level
3. Explore factors such as barriers and facilitators that influence the operationalization of the IDS system
4. Explore the role of NPHIs and other key stakeholders in central surveillance coordination, and decision making
5. Explore key stakeholders’ ideas on how to move forward and improve the IDS system.

Table 1. Demographic and health systems information relevant to the seven participating NPHIs

Characteristics	Participating NPHIs						
	Public Health Agency of Canada	Public Health Institute of Malawi	Instituto Nacional de Saúde, Mozambique	Pakistan National Institute of Health	Public Health Agency of Sweden	Uganda National Institute of Public Health	UK Health Security Agency
Abbreviation	PHAC	PHIM	INS	NIH	PHAS	UNIPH	UKHSA
Year established	2004	2013	1976	1980	2014	2013	2021
Country	Canada	Malawi	Mozambique	Pakistan	Sweden	Uganda	United Kingdom
Population	38.9 million	21.5 million	33.2 million	230.6 million	10.2 million	49.0 million	68.7 million
System of government	Federal	Unitary	Unitary	Federal	Mixed	Unitary	Unitary
Accountability	Federal Government via the Minister of Health	Ministry of Health	Prime Minister (technically supervised by the Minister of Health)	Federal Government	Ministry of Health and Social Affairs	Ministry of Health	Parliament via the Secretary of State for health and social care
Relation to IDS system	Shared responsibility for public health, including disease surveillance with provinces, territories, and other partners	Manages and coordinates IDS, including One Health Surveillance Platform, at all levels (health facility, district, provincial, national)	Most experienced partner in terms of surveillance, and implementation of surveillance at the Health Unit level	Initiated an IDS system with the technical assistance of the UKHSA; implemented in 54 out of 156 districts distributed across the country	National statistical authority responsible for health statistics within infection control and public health	Surveillance department is nested under the mandate of the Ministry of Health	Responsible for public health protection and infectious disease surveillance and response in England; also collaborates with NPHIs in devolved nations (Scotland, Wales and Northern Ireland)

# 3. METHODOLOGY

The conceptual framework in Figure 1 guided the development of a standardized topic guide used in each of the deep dives. The thematic areas covered in the topic guide are provided in Annex 1. The framework is based on the initial WHO IDSR framework and incorporates Morgan et al.'s (2021) five principles of IDS to present an integrated vision of an IDS from organizational and operational aspects. It comprises five key domains: 1) governance, 2) system and structure, 3) financing, 4) core functions, and 5) resourcing requirements. The effect of integration and coherence across these five key domains, and the sub-domains captured in Figure 1, as well as the complementarity of each domain supporting the IDS operationalization in deep dive countries, were explored as part of this workflow.



Figure 1. Conceptual framework of IDS developed for the project

## 3.1 Participants

Deep-dives were conducted in five key steps from mapping (Step 1) to qualitative data collection (Step 2), within-case analysis (Step 3), a validation workshop (Step 4), and cross-case analysis (Step 5). The approach to conducting the deep dives, including the specific methodologies, is described in detail in the project protocol<sup>2</sup>. To summarize, the approach involved a case study methodology –

<sup>2</sup> Deep dive protocol, version 6.0.

with each country comprising a “case” – and used a combination of focus group discussions (FGD) and key informant interviews (KII) to address the workstream objectives.

The deep dives were done jointly in a twinning partnership with another NPHI as part of efforts to share learning, as well as introduce independent input into the data collection and analysis process. The lead NPHI-partner NPHI pairings were as follows: Malawi-PHI and Norway, Mozambique-PHA and Sweden, Uganda and US CDC, Pakistan and UKHSA, England and PHA Canada, Canada and UKHSA, Sweden-PHI and Norway.

The countries selected for the deep dives were selected to get both high- as well as lower- and middle-income countries, across different world regions. Local participant selection was also purposeful, seeking to recruit participants from across different administrative levels (national, regional, provincial and local), across a range of sectors (human health, animal health, environmental health, NGOs, etc.), as well as both urban and peripheral regions.

### **3.2 Data Collection**

The indicative target for each country was ideally 15 FGDs and KIIs in total. It was anticipated that the FGDs and KIIs would take around an hour and be done either remotely or face-to-face. In the event, the deep dives in Canada, Sweden and England were completed remotely online and face-to-face, whilst the other deep dives in Pakistan, Malawi, Mozambique and Uganda were done predominantly in country face-to-face.

Prior to data collection, a briefing and training workshop was conducted remotely via webinar so that project leads, and staff were familiar with the study aims and methodology. A topic guide for the FGDs and interview was also devised and shared with project teams. The topic guides included a series of open-ended questions, and there was flexibility for project teams to iteratively adapt questions and develop further sub-questions to explore emerging themes based on the context where and with whom the FGDs were held. This iterative flexibility to the topic guides was deemed essential in view of the diversity of country contexts anticipated. Topic guides were sense checked and piloted by the Pakistan data collection team to check for clarity and appropriateness.

Data collection was conducted by NPHI data collection teams in each of the deep dive countries. Each team would at the very least have one facilitator and one note-taker. Audio recordings of FGDs and interviews were advised, but not mandatory, to facilitate notetaking later as needed. Teams were advised of the importance of good data management practices (e.g., issues of anonymity, confidentiality, and data security), as well as to be alert to possible positionality bias in data collection to minimize this risk of bias in data collection.

Throughout the data collection period, regular weekly meetings were held with country leads to share updates and discuss solutions to issues encountered. Emerging findings were also discussed. The outputs of the data collection process were summaries of the FGDs and interviews, as well as a country report (appendix 2) prepared by the local NPHI team who had processed their data and summarized their findings. These outputs were then shared with the analysis team (in Step 5) who carried out the multi-country deep dive syntheses of all the deep dives, which is detailed in this report.

### **3.3 Ethics**

Prior to the conduct of the deep dives, ethics waiver was sought and granted by the institutional ethics review board for Emory University, an IANPHI member, on behalf of IANPHI.

### **3.4 Approach to the Analysis and Synthesis of the Deep Dives**

Between May and September 2022, the lead NPHIs in each of the deep dive countries conducted a series of FGDs and KIs.

In July 2022, an evaluation and analysis team were established to support IANPHI and the participating NPHI teams in synthesizing key findings across the deep dives. This synthesis focused on identifying characteristics of IDS systems that are similar and different across contexts, common enablers, and barriers to strengthening IDS, and developing key recommendations based on lessons drawn from the diversity of contexts.

The analysis and evaluation team received typed summaries of the 34 FGDs and 48 KIs, as well as summary reports from the participating deep dive countries. These typed summaries formed the basis for data analysis via the IANPHI Project Management Office (PMO). These summaries formed the initial dataset that the team used to begin the analysis. To standardize the analysis, the team adopted a deductive approach and created a framework matrix in Excel using the five workstream objectives as column headings. Each member of the team led the data extraction and charting for a subset of the participating NPHIs in order to efficiently manage the dataset. Each team member identified major themes and sub-themes for their subset of countries, before coming together to discuss themes across countries. In addition to the FGD and KI summaries, the analysis and evaluation team received the country report, other summary documents, and meeting materials prepared by the lead NPHI teams and the IANPHI IDS PMO, which were used to inform the analysis and synthesis of the deep dives.

Table 2. Number of FGDs and KIIs conducted for the deep dive in each country within timescale of the project

Lead NPHI	Country	Number of FGDs	Number of KIIs	Total
Public Health Agency Canada	Canada	7	3	10
Public Health Institute Malawi	Malawi	6	9	15
Instituto Nacional de Saúde	Mozambique	2	5	7
National Institute of Health	Pakistan	4	8	12
Public Health Agency of Sweden	Sweden	5	4	9
Uganda National Institute of Public Health	Uganda	5	9	14
UK Health Security Agency	England	5	10	15

Each member of the analysis team led the data extraction, charting, and analysis for a subset of the participating NPHIs to efficiently manage the datasets. To standardize the analysis, the analysis team created a framework matrix in Microsoft Excel using the five workstream objectives (as column headings). Following creation of the matrix, the analysts extracted data from the FGD and KII summaries that were relevant to each of the five objectives and charted the data into the Excel-based matrix for analysis. The analysis team then identified themes per country and numbered the themes according to objective to facilitate cross-country comparisons and synthesis of major themes across countries. Analysis of the data and identification of themes ceased when thematic saturation had been reached, and new data analyzed did not shed further light on the themes that had already been identified from the analysis.

In addition to the FGD and KII summaries, the analysis team received other reports, summaries, and meeting materials prepared by the lead NPHI teams and the IANPHI IDS project management office (PMO) which were used to inform the analysis and synthesis of the deep dives. Two group discussions were also held on the September 29 and October 5, 2022. Representatives of the data

collection teams from every country involved presented and discussed each country's deep dive outputs and identified the common themes and variances. This report contains findings from the synthesis of the findings from the deep dives.

### **3.5 Limitations**

One recognized limitation of the deep dive study is the issue of representativeness as only seven countries were covered, with no representation from other regions such as the Western Pacific, Southeast Asia, or South America. Data collection had to be conducted by separate in-country teams organized by the respective NPHIs due to logistical and time constraints for this study. Efforts were made to standardize data collection, but some variation in approach was likely. A more robust approach would have been for a single team to collect data in all the countries involved to ensure consistency. There are, however, advantages to having trusted local NPHI teams carry out data collection, such as familiarity with local context, culture, norms and language. There was also some variation in the volume of data collected by country, with the total number of FGDs and KIs ranging from 7 to 15 per country (average of 12 per country). Within countries it is possible that not all key stakeholder perspectives were captured, and there is the possibility of response bias in those who did participate. There were variations in how comprehensively the summaries of the FGDs and KIs were prepared, for example some summaries had detailed narrative text for each objective while other summaries had less detail. Another issue of note was the fact that HIC participants were generally unfamiliar with the term IDS or the WHO IDSR strategy. When conducting the discussions and interviews, IDS had to be paraphrased to "integration of disease surveillance" which participants were able to engage with.

## 4. RESULTS

The results are divided into two sections: the first summarizes key findings within countries (prepared by the local NPHIs teams), and the second presents the synthesis of key findings across countries by Objective (prepared by the analysis and evaluation team).

### 4.1 Key Summary Findings Identified from the Country Deep Dives

#### 4.1.1 Malawi

In 2002 Malawi adopted the IDSR strategy developed by WHO AFRO and adapted its 3<sup>rd</sup> edition technical guidelines in 2020. The Public Health Institute of Malawi (PHIM) is responsible for IDSR, including the e-IDSR through use of the One Health Surveillance Platform (OHSP). The OHSP aims at including information from human and animal health, including laboratories. The Health Management Information System (HMIS) run by the Ministry of Health (MOH), also uses DHIS2 and collects much of the same information as IDSR. For some priority diseases (EPI, HIV, Malaria, TB, and Schistosomiasis) the MOH has established dedicated disease programs, which include surveillance.

The MOH is responsible for surveillance of human health and PHIM, as a directorate in the MOH, is responsible for IDSR. However, HMIS and the disease programs are organized at different sections of MOH, and their donors have an influence on the programs. PHIM plays a central role in surveillance in the country and has several efforts to improve surveillance and digitalization, e.g., integration of information from various sources, including the animal sector and laboratories into the OHSP using the DHIS2 software. There is much parallel reporting in the vertical systems, and room for improvements of human-animal health integration. All major stakeholders voiced an openness and willingness to cooperate better, share data and improve surveillance.

The vertical disease programs receive significant external funding, but support for national IDSR and HMIS programs is minimal. The quality of surveillance data correlates to the level of financing. There is a lack of adequate and up to date digital equipment, capacity of electronic data transfer, and weak server capacity. There is a great need for access to improved and simplified guidelines, especially at facility level, training of staff at all levels, and improved infrastructure and data quality systems. At facility sites and at district level better systems for collaboration and sharing of data is needed. Laboratory systems need to be strengthened and laboratory data better integrated. One major concern is inadequate data quality in the IDSR due to lack of supervision and tools. Data being

reported is sometimes not clear because the case definitions and diagnostic codes are not easily available at point of reporting or in the reporting forms. This is mainly due to lack of financial resources to scale up orientation, trainings, and to make these available at health facility level, but also inadequate quality routines. For outbreaks and emergencies, the rapid response teams communicate well through WhatsApp.

The main recommendations that emerged from the deep dive in Malawi coalesced on two main themes: how to better integrate national surveillance systems, and how to improve data quality. The key recommendations for policy and practice were:

### Integration of surveillance systems

- i. Reduce parallel reporting in the vertical disease surveillance systems. There is room for improvements to human health-animal health surveillance integration.
- ii. Establish a formal collaboration among IDSR, HMIS, EPI, HIV, TB, malaria, animal health etc. to promote integration in order to: a) better understand each other's surveillance systems; b) agree on common case definitions and reporting frequencies; c) rationalize reporting requirements so that only one data input is required from a reporting facility; and d) strengthen interoperability of LMIS (laboratory data) with DHIS2/OHSP.
- iii. There is a great need for access to improved and simplified guidelines especially at the facility level, the training of staff at all levels, as well as improved infrastructure and data quality systems. At facility sites and at the district level better systems for collaboration and sharing of data is needed. Laboratory systems also need to be strengthened and laboratory data better integrated.
- iv. PHIM to lead a national process on aligning the list of reportable diseases to the reporting forms, including the frequency of reporting (immediate, weekly, monthly, and quarterly).

### Data Quality

- i. Improve data quality at facility level including case definitions and provide training to community level and primary care professionals.
- ii. Improve data quality by establishing systems to ensure validation of data reports at district and national levels.
- iii. The vertical disease programs receive much external funding, whereas the national programs IDSR and HMIS support is minimal which needs to be improved. Quality of the surveillance data is, to a large extent, reflected by the level of financing.

#### 4.1.2 Uganda

There are several sector-specific disease surveillance mechanisms at varying stages of development and effectiveness that are being implemented in the country. The human health sector has a developed IDSR system supported by WHO and other partners. The animal sector has systems that report information from the district level. There is however limited interaction between the different surveillance systems despite the existence of a One Health platform. The One Health mechanism being coordinated by UNIPH has potential for defining, advocating and expanding acceptance for integrated disease surveillance and its implementation across the country. There are relatively well-developed human resource capacities for IDS at the national level but inadequate at the regional and district levels across sectors. There is limited national government financing for surveillance activities across sectors – over 80% of surveillance and response funding is from external development assistance.

Digitization of the surveillance systems is ongoing and has been accelerated in the era of COVID-19. However, structural bottlenecks hamper institutionalization. There is limited political and leadership awareness of the role IDS plays in disease control. This has since changed due to COVID-19. It is hoped that this will lead to better financing of IDS across all sectors and improvements in human resource and infrastructure.

The key recommendations for policy and practice are:

- i. Strengthen IDS data integration across and within One Health sectors
- ii. Accelerate digitization, interconnectivity, and inter-operability of surveillance systems
- iii. Focus resources at building resilient sub-national capacities for IDS
- iv. Build laboratory capacity for other One Health sectors
- v. Advocate for increased national government funding for IDS

#### 4.1.3 Mozambique

The advent of HIV has introduced surveillance systems that go beyond surveillance to the use of electronic patient tracker systems that are not government owned. The humanitarian crisis that followed the war in Cabo Delgado has also catalyzed the multiplication of surveillance systems by donors and the private sector. These systems do not share data with MOH or other government institutions further increasing the gap for an IDS system.

COVID-19 introduced the need for real-time data for decision-making, changing the perspective in which surveillance is made in the country and broadening the vision for integrated systems and the use of electronic platforms. There is fear that this learning curve will soon be forgotten with the

reduction of COVID-19 without making positive changes to the way surveillance is implemented. Governance played a key role in COVID-19 surveillance. The existence of a legal framework that governs IDS is key for policy change, advocacy for human capacity development, and identification of funds for IDS.

The country deep dive revealed a different level of understanding and conceptualization of both the definition, and roles of an IDS system. Existing systems are not mapped and when identified are not integrated into one system that can provide information in both specific and cross-cutting surveillance areas. Those working in one province cannot view the data of another neighboring province. Integration does not exist even within MOH lead programs.

The key recommendations for policy and practice are:

- i. **Governance for IDS is key:** All (MOH, INS and other government institutions and partners including NGOs and CSOs) would benefit from a regulation or guidance document, and procedures that coordinates data collection and submission to a central repository for use.
- ii. **Resources are needed:** Financial resources, data centers, training, and equipment are essential for IDS. An IDS unit would need to be developed or supported. INS has a few initiatives that can be easily transformed into an IDS.
- iii. **Technical assistance:** The country may benefit from technical assistance that provides IDS training and vision development, and implementation with a hands-on approach. Several times projects finish without proper transition or hand over to the country team. The approach should be of technical assistance from the very beginning with all functions being developed by and in the country. As best practice, the development of a framework led by MOH and/or INS to map, catalogue, receive data, and conduct analyses and visualizations is needed. To give further richness and breadth to existing data, data from morgues and animal health authorities would give insight to disease origin and impact.

#### 4.1.4 Pakistan

Health policymakers have a good understanding of the concept of IDS which provides a conducive environment for improvement of the system. However, it was evident that others had a poor understanding of the concept of integration. Some participants either saw integration as data sharing or equated it with collaboration.

IDS is partially implemented in the country. The current model of IDS is well-thought out and planned with availability of all essential/required tools and supported by a developing network of public

health laboratories. However, there is a dire need to consider IDS as a priority by the government as the existing IDSR is not utilized at its maximum capacity, and it is only implemented in some parts of the country. The future continuity of IDS depends on secured, sustainable funding through the government.

The key recommendations for policy and practice are:

- i. The current IDSR program needs to be extended across all parts of Pakistan, both in terms of its coverage in all districts as well as fulfilment of all its components.
- ii. Standard and uniform tools should be applied across the country.
- iii. Government commitment and sustainable financial support for the provision of resources is needed.
- iv. The work of laboratories needs to be further expanded to develop networks of laboratories and include the laboratory system in surveillance activities alongside any other possible source generating disease data.
- v. Surveillance hubs need to develop expertise on analysis and interpretation.
- vi. Advocacy should be initiated for political and institutional ownership of the IDSR system to strengthen the existing IDSR and to further expand IDSR consistently across the country with support of specific legislation which should also cover private sector
- vii. Further research is required to identify and propose models for integration of vertical programs. This may also include scenarios where duplication of system/data sharing has occurred.
- viii. All provinces talked about developing skillset of the staff. It would be beneficial to explore what the specific gaps in training are and how this can be best addressed.
- ix. The federal system and provincial autonomy are challenges, but the National Public Health Institute can overcome this by strengthening coordination by adapting the National Command and Operation Centre (NCOC) model used in COVID-19.

#### **4.1.5 Sweden**

Sweden has well-functioning systems for sharing, integrating, and using data in surveillance and response, but also potential for improvement. The legal framework and a network of many different

actors facilitate the collection of data, and many technical solutions are in place enabling the integration of different data sources. The legal framework for handling the many data sources available gives a clear mandate and responsibilities to the participants in the network of agencies responsible to collect and handle data. The strong legal system gives stability but also makes changes and adaptations difficult.

The disadvantage of the legal framework is that integration is often cumbersome, slow and resource intensive. When there are new needs for surveillance it can take time to implement and get it to work. Data ownership occasionally translates into protectiveness of the data, adding to the difficulties of sharing data. As the legal system partly follows the same vertical structures as the health system, the overreaching legal framework that enables data sharing across actors is sometimes difficult to implement in an efficient manner. Together they make for a robust but conservative system.

Due to the decentralized health-system in Sweden, with an autonomous regional level, it is difficult to collect some health data at a national level. Coordinated evaluation of the surveillance system in Sweden is not done on a routine basis. Different IT systems and ownership issues are part of the problem. Nevertheless, during the pandemic collaboration was mostly smooth owing to the personal efforts by different actors to find new ways to work towards a common goal. Development of clear structures for coordination, evaluation, and follow-up of the systems could assist in identifying and solving some of the existing barriers.

The Swedish system also has a unique identifier for everyone which gives the unique possibility for further developing an IDSR system using different registries as sources for surveillance. This reduces the burden of manual reporting for healthcare workers, increases the quality of data provided complete data on national level, and improves timeliness.

The key strengths of the Swedish system build on the following cornerstones:

- i. A strong legal framework for data handling and collection within each agency
- ii. A network of agencies that collects and handles different types of data
- iii. A highly developed collaboration within the network between these actors that makes informal integration of data possible
- iv. Unique identifiers that make integration of data from different sources possible

There is an opportunity to improve access to different data sources in Sweden to facilitate timely and effective integrated surveillance activities to inform public health decision making. The existing model for data access and sharing based on legally defined responsibilities for different stakeholders gives a strong but conservative structure for the network of agencies collecting data that can be used for integrated surveillance. To further improve this and give a more agile possibilities to share more data

in a timelier manner. The existing system with common identifiers in different data bases makes integration possible despite the lack of a common system but important data sources are not accessible are not included. Important ones are for example data from health care and the health system where only selected data can be access makes further development of an integrated system difficult. A comprehensive national governance model with agreement on standards, principles, code of conduct, privacy and protection legislations would promote stronger surveillance integration.

The key recommendations for policy and practice include:

- I. Improve access to different data sources through legal frameworks on data access and sharing
- II. A comprehensive national governance model to provide stronger surveillance integration
- III. Routine coordinated evaluation of IDSR
- IV. Improve co-ordination of sub-national health data to national level systems created through decentralization and different ownership and IT systems
- V. Research into the role of social media in surveillance.

#### **4.1.6 England**

England does not have a single integrated disease surveillance system, but it does have multiple disease-specific surveillance systems, many of which are well developed and established, with varying degrees of integration, and ways of sharing data and intelligence across organizations and platforms when needed. The current disease specific systems are flexible enough to be scaled up during enhanced incidents, but there is room for improvement, in terms of increasing automation, navigating information governance regulations to allow for timely sharing of data while protecting the data and confidentiality of subjects, and improving standardization.

Data sharing relies on good relationships between UKHSA, other organizations, and data collectors and reporters, but expert analytical input is also required to ensure appropriate interpretation of surveillance data. There is a considerable amount of data, but limited analytical capacity, hence prioritization of disease areas and surveillance activity is needed. Integration is not an end itself, but clarity is needed of the intended outcomes sought through integration.

UKHSA has limited authority to mandate integration of systems or standardization of processes in other organizations, so an enabling legal and regulatory framework could help facilitate this. Any significant changes to the current system would require political will and support, funding, and clarity of organizational governance structures. However, public health system reorganizations hinder system integration. Integration may be desirable, but it is not easily realized due to the plurality of systems, insufficient standardization, but also different users of surveillance outputs have different needs.

While there is currently no single overarching governance structure for human health surveillance, there are lessons to be learned from the animal health system where there is a single overarching governance structure across the four nations of the UK, which facilitate better data sharing, awareness, and determination of priorities. This type of governance structure for human health would improve integration of not just disease data, but also environmental health and non-communicable diseases.

Another key area would be the need to further study the value of integrated disease surveillance in systems with good disease prevention/mitigation and preparedness measures, particularly in terms of cost-benefit. It would be important to understand where integration adds value and how it achieves intended population health outcomes. Integration is difficult and further study would be useful to understand from past projects how the integration of systems can be successfully operationalized.

The key recommendations for policy and practice are:

- i. Clearly defined outcomes/purpose for integration and surveillance is required, which will guide prioritization of activity. There is a need to consider the diversity of users and their requirements, as well as the changing surveillance technology landscape in England, and to communicate the benefits of integration to stakeholders.
- ii. Develop an overarching governance structure to support UKHSA's influence on surveillance and its integration, including clear roles and responsibilities for all key actors involved.
- iii. Further research needed to understand the cost-effectiveness of IDS and how best to operationalize it.
- iv. Widen the scope of surveillance activities to include more animal health, environmental health and non-communicable diseases.
- v. Build collaborative relationships and networks to support surveillance activities.
- vi. Increase public involvement in surveillance.
- vii. A strong and sustainable workforce with key skills including enhanced training of surveillance workforce in microbiology, virology, parasitology, mycology, epidemiology, infectious diseases, and public health
- viii. Better data flow, traceability, standardization and automation of processing.
- ix. Sustainable funding covering innovation and long-term activities

#### 4.1.7 Canada

Canada's participation in IANPHI's IDS deep dive research project generated valuable insights into the IDS landscape in Canada, barriers and facilitators of IDS, and recommendations for IDS.

Participants in this study included individuals with IDS subject matter expertise from the Public Health Agency of Canada (PHAC) and provincial and territorial representatives. While many successful examples of IDS were identified in Canada, participants emphasized the need for a comprehensive definition of IDS to assess the level of IDS across surveillance systems.

Key barriers for IDS were: (1) challenges with coordinating a federal/provincial/territorial approach, (2) lack of seamless data sharing, (3) limited scope of surveillance infrastructure, (4) lack of sustained funding, and (5) public health surveillance workforce challenges. Key facilitators for IDS were: (1) collaborative relationships, (2) data sharing solutions, (3) federal surveillance supports, (4) dedicated networks for integration, and (5) boosted funding.

There is an opportunity to improve existing surveillance governance infrastructure in Canada to facilitate timely and effective integrated surveillance activities to inform public health decision making. A comprehensive national governance model where responsibilities for different stakeholders is clearly defined, along with agreement on standards, principles, code of conduct, privacy and protection legislations would promote stronger surveillance integration. Establishing an independent and competency-based Information Stewardship Council to foster stewardship of the health data foundation and provide advice on health data investments to jurisdictions and First Nations, Inuit and Métis Nation representative bodies is recommended here, which mirrors recommendations by another report recently released by an expert advisory group in Canada on health data governance improvement.

The key recommendations for policy and practice include:

- i. Developing an international framework and/or definition for IDS
- ii. Streamlining data sharing processes
- iii. Enhancing surveillance infrastructure
- iv. Investing in collaborative partnerships

## 4.2 Results of Synthesis Analysis

The following section contains the results of the deep dive synthesis organized by workstream objective. The key findings outlined in **Objectives 1 and 2** relate to how current surveillance systems are functioning, and the extent to which IDS systems have been developed in each of the deep dive countries. Many of the findings identified in relation to these first two objectives reveal some of the barriers and facilitators influencing operationalization of an IDS system, and these are further detailed

in **Objective 3**. The COVID-19 pandemic was an important reflection point for all countries, and its impact on surveillance systems in terms of how it acted as a barrier and/or facilitator is captured in Box 1. Across countries, **Objective 4** on the role of the NPHI in coordination activities and decision-making was not discussed in as much depth compared to the first three objectives and is clearly an area for further exploration. Finally, **Objective 5** is a synthesis of the main types of recommendations shared by each deep dive country.

#### **4.2.1 Objective 1: Understanding of current surveillance systems and extent to which IDS systems have been developed in each country**

**In all countries, there is no singular, fully established and functional integrated surveillance system.** Some deep dive participants questioned whether a singular IDS system is feasible or necessary, especially when there were several surveillance systems identified in Canada and the UK that are well established and well-functioning that can integrate multiple sources of information to achieve a specific goal. Surveillance in several countries was reported to be fragmented across multiple separate surveillance systems. The fragmentation in some countries was exacerbated during the COVID-19 pandemic as many different organizations and specialist agencies set up independent systems for data collection and analysis, which poses a coordination problem in terms of how information is being analyzed, interpreted, and disseminated. Fragmentation created access problems during the pandemic, whereby data could not be accessed quickly, and information flow was not streamlined. To contrast, there are fewer actors involved in surveillance of non-communicable diseases (NCD), which has made integration of surveillance data for NCDs easier.

**Integrating surveillance systems requires coordinating stakeholders, who have differing needs, and ensuring routine representation from different sectors in national surveillance activities.** In most contexts, the level of multisectoral and transdisciplinary collaboration required for integration of surveillance data has not been routinely achieved. Typically, key sectors and stakeholders meet on a needs basis to discuss specific disease threats, rather than to discuss surveillance.

There were six key overarching issues to establishing IDS systems, and they related to:

1. Lack of clarity of reasons for and value of an IDS system
2. Unclear ownership and lack of incentives to manage a change in surveillance practices
3. Incompatibility of existing IT systems and infrastructure
4. Workforce and skills required
5. Challenging legal environment to facilitate information and data sharing between and within agencies
6. Lack of funding and investment to drive integration.

These issues are introduced below, and being described in more detail under Objective 3.

1. The first major issue is the **inconsistent understanding** of what integrated disease surveillance should encompass. In both the high- and lower-and-middle-income countries studied, there are many surveillance systems that fully operate as self-contained systems. There was lack of consensus as to whether integration meant that all systems were to be part of one unified system or if integration was simply equivalent to the summation of data. Determining the goals of integration and how do we achieve those were felt to be more important. Surveillance systems in deep dive HIC have been established without full integration. While IDS may be desirable, it is not necessarily essential (depending how IDS is defined and the aims of the proposed IDS system). However, there is value in considering whether and how existing surveillance systems can be strengthened and the extent to which integration of aspects of existing surveillance systems will increase the efficiency, effectiveness and utility of data collection, analysis and use. Additionally, IDS as a system for all threats versus a primarily infectious disease and indicator-based system seemed to not fit the needs of some countries considering IDS.
2. The second issue is the lack of clarity surrounding who (which stakeholder) is ultimately **responsible** for integration, which also raises questions of **ownership and leadership** in transitioning to IDS, particularly given the fragmentation and proliferation of different surveillance systems.
3. The third issue common to many of the countries studied is the incompatibility of IT systems, and the lack of IT infrastructure to support integration, which hinders **interoperability**. This also creates problems with ensuring **data quality** (e.g., reliability, accuracy) where integration is concerned, and maintaining integrity (e.g., completeness, consistency, context) of data in a merged system.
4. Fourth is ensuring data quality, integrity, analysis and evidence generation in an integrated multi-source system requires dedicated (human) resources to conduct the proper quality assurances and analytical skills, and this in turn requires **training and skills-building**. A specialized **workforce** – who can process, analyze, and interpret integrated surveillance data – is an essential function of an IDS system, and highlights the need to conceptualize IDS beyond just the integration of datasets.
5. The fifth issue is the governance of different datasets by **different legal frameworks**, and data sharing requires agreements, such as Memoranda of Understanding, within and between agencies to be in place. While this is important in all countries, it is a significant impediment to integration in federal systems (e.g., Canada and Pakistan) where subnational entities must legislate privacy agreements with national entities. Where surveillance is also funded by

development partners, the legal arrangements in place with local agencies means the data cannot necessarily be used without the partner's permission.

6. Finally, there is the lack of sustained **funding and investment** in coordinating different surveillance systems. This also includes looking ahead to new technology-driven surveillance for better precision in disease tracking and outbreak management; to get ahead of health emergencies, investments in laboratory surveillance including genomic surveillance and data sharing platforms are needed. Sufficient funding and investment over time, such that it is sustainable, requires **political motivation**, which is often also lacking and particularly during 'peacetime'. The lack of sustained, stable funding and resourcing is common to all the countries studied but felt most acutely by the LMICs.

#### 4.2.2 Objective 2: Types of surveillance programs in each country, including how they have been implemented and integrated at a national level

Surveillance systems have been described in three layers: the data collectors (data inputs), the surveillance experts (analysis and outputs), and the sponsors (decision-making and policy implications).

While many interviewees across countries thought of surveillance as largely ground-up and, in most countries, there are strong systems and mechanisms in place for data collection and analysis locally, integration depends on those with decision-making roles (political and financial) to ask the right questions, seek the right answers, and to facilitate the transition to IDS. However, there are weaker feedback loops in place to ensure communication systems work top-down (as well as bottom-up). In some countries, however, there are human resource gaps in the first two layers of surveillance (i.e., data collectors and surveillance experts), both in terms of number of staff as well as technical expertise, that affect the extent to which surveillance data is analyzed and reported in a timely manner and thus, more importantly, the ability of the public health system to respond to potential threats. There is also a key role for surveillance experts to play in advocating for integration to decision-makers. Finally, there are varying degrees of devolution and regional disparities in surveillance across the countries. In Pakistan and Canada, for example, devolution to the provincial and territorial levels means that there is a lack of national-level authority for coordination and standardization.

The COVID-19 pandemic revealed some limitations in terms of how well surveillance data can inform broader public health issues. The type of data that was collected through existing surveillance systems during the pandemic was not able to identify and understand patterns of risk and vulnerability at a sufficiently granular level, which was key to tailoring response efforts to certain populations or geographic areas. Some datasets needed to be manually enhanced with additional information, such as location, to be useful for contact tracing. The pandemic also shed light on the

potential role of harnessing non-traditional sources of surveillance data, via social media for example, and the need to evaluate their relative utility moving forwards.

**For some countries, there was no formal system or mechanism for sharing data and intelligence across agencies. Interpersonal relationships and networks were key to data sharing.** These relationships and networks facilitate sharing and, where there is trust, stakeholders have a high degree of willingness to work around the various impediments encountered. However, it also poses challenges to the consistency of information shared, and the sustainability of informal sharing mechanisms that are dependent on individuals instead of mechanisms/processes among institutions. Formal systems or mechanisms for information and data sharing across sectors and stakeholders that exist are more often disease-specific, rather than broadly focused on surveillance. There is increased interest and effort to integrate different surveillance systems during outbreaks, but this momentum is lost once the outbreak has been managed. This suggests that the current use-case for more integrated surveillance in most contexts is driven by there being a clear and urgent need for it, rather than establishing integrated surveillance systems as part of routine public health and health emergency preparedness and management.

**The One Health approach can facilitate multisectoral and transdisciplinary collaboration, and integration of surveillance and information systems across the human health, animal health, and environment sectors.** However, there are challenges to operationalizing the One Health concept. The human health (or public health) sector was often criticized for excluding the other two sectors from planning and coordination of activities and was said to have particularly weak relationships with the environment sector at a national level. At a local level, or the first 'layer' of surveillance as previously described, there appear to be stronger relationships and coordination between the human / public health, animal health, and environment sectors than compared to how these sectors engage at a national level, though in Malawi for example, there was much fewer resources and staff for environmental and animal health compared to human health, which hindered joint surveillance activities.

**It is important to also consider integration of public and private surveillance systems, especially in countries where a substantial proportion of healthcare is through private providers** (such as Pakistan). Although data from the public laboratory system feeds into national databases, there is no formal mechanism for feeding data from private laboratory systems into the same nationalized databases in countries where private-sector data is generated. In several countries, it is a challenge not only to have private laboratories reporting, but also private health facilities to provide clinical reports, even if it is mandated by law.

The issue of integration and interoperability of surveillance systems across borders was also raised for further consideration, given the lack of mechanisms to support this currently in the majority of countries.

#### **4.2.3 Objective 3(a): Barriers influencing the operationalization of the IDS system**

**An important barrier that all the highlighted countries confront relates to how IDS is conceptualized, both within and across different contexts, as IDS does not necessarily mean the same thing depending on context, sector, or stakeholder.** There was a lack of clarity surrounding what IDS is from a conceptual and operational perspective. There was an expressed need to define key concepts and establish a common understanding of IDS that can be operationalized at national and subnational levels. Part of this conceptualization phase needs to address how knowledge, expertise, training and skills-building, and communication would also be integrated, which are currently neglected dimensions in integration. Interviewees in Mozambique and Uganda further commented on the need to clarify the governance and reporting structures that would be involved in an integrated system, particularly as there can be confusion in roles and responsibilities between national and subnational surveillance systems presently. Thus, integration must be conceptualized across a spectrum of systems, capacities and activities, and the integration of these different dimensions will also require sufficient attention and resources. Integration must be thought of as more than simply the integration of data and IT infrastructure.

**While a legal environment that supports data access and sharing across agencies is an important facilitator, this type of environment does not exist in most countries and is, instead, a major barrier.** Interviewees from all countries described the need for an overarching, national view of the laws and regulations available and, where there are gaps, on the storage and handling of data across regions, sectors, and agencies. The UK's recent departure from the European Union and the recent devolution of government in Uganda were mentioned and highlighted the dynamic nature of countries' political and legal environments, and the need to consider these dynamics when planning an IDS system to ensure it is both resilient to macro-level governance changes and adaptive. Further, in countries with a federated<sup>3</sup> system like Canada, the surveillance authority is devolved and decentralized so privacy laws must be developed to grant one entity at the federal level access to data. This must be supported and based on trust, not just laws.

**The political and economic implications of surveillance data were highlighted as additional barriers to strengthening surveillance systems.** For example, interviewees in Sweden highlighted how the proliferating of surveillance data during the pandemic made it challenging for public health authorities to openly and transparently report on data collected through surveillance. In Uganda and the UK, interviewees discussed the economic implications of reporting certain diseases, particularly

---

<sup>3</sup> Provincial, state, cantonal, territorial, or other sub-unit governments

on the animal health side, in terms of considering how much data and information they should share with other key sectors and stakeholders. In contexts where key decision-makers do not understand how existing surveillance systems function, or what the value of integration would be, there is an **absence of political will** to establish an IDS system. Further, in Uganda, the lack of communication, or “weak” communication, between ministerial agencies was cited as an important barrier to integration. Interviewees suggested educating (e.g., raising awareness, advocacy) key decision-makers on the importance and value of IDS as a way of creating a more favorable political (and financial) environment to operationalize IDS.

Interviewees in Pakistan and Uganda also found there to be a general lack of motivation to report surveillance data and to provide the required information to the right stakeholders. There was also the additional issue that some decision-makers do not understand the importance or value of surveillance. In Uganda specifically, interviewees described this as an ‘*attitude gap*’ whereby individuals choose not to learn the systems of surveillance, even if it is a required part of their job description. In Mozambique also, interviewees found that those involved in surveillance only understand what happens at their level (e.g., district, provincial). The motivation and attitude issues reported in these two countries suggest the need for enhancing education, training, and skills development of the surveillance workforce, as well as understanding other additional factors that would improve motivation, in addition to key decision-makers on the receiving end of surveillance data. Also, if there is not a feedback loop for surveillance data back to the original reporter, they often will not understand its value. As one interviewee in the UK reflected, data sharing requires willingness from key stakeholders in different sectors (within agreed legal frameworks and mechanisms of communication).

**Most countries found that sustainable funding for existing surveillance systems, as well as funding for a fully interoperable system, was wholly inadequate.** These domestic funding constraints have weakened or limited the potential capabilities of existing surveillance systems, and hampered discussions on establishing an IDS system. In some countries, such as Uganda and Malawi, surveillance activities receive and are driven by external donor support, however, this type of funding is typically earmarked for specific activities and donor-driven interests. Some countries (Pakistan, Mozambique) are reliant on external support to develop and sustain surveillance systems. In all countries, regardless of their overall governance structure (i.e., federal, or unitary), disbursement of funds for surveillance activities - and public health more broadly - is top-down and thus, requires support at a higher level of government to develop an IDS system. This poses a few barriers: the first is that the support received from one government might not exist when there is a change in government; and second, public health agencies spend significant time and resources applying for funding and justifying the need for it. As one interviewee in the UK reflected, there is far less interest in funding surveillance compared to research and development (R&D). The fact that funding for surveillance activities is not guaranteed, nor is it long-term, highlights the wider issue of sustainable

financing for existing surveillance systems, as well as future integrated systems. Given these financial constraints, and the inadequacy of funding for existing public health surveillance activities, questions were raised about where additional funding for an IDS system would even come from.

**Important questions regarding the ownership and ultimate responsibility of an IDS system were raised given the fragmentation of current surveillance systems and the multiple ‘owners’ – public and private, at national and subnational levels – of current surveillance data.** There was a lack of clarity surrounding who would take overall leadership for setting up and operationalizing an IDS system. In Canada, one interviewee stated that “figuring out a way to move forward with a federated public health system where information can flow from local to provincial to federal, piece by piece, without every item needing permission. That is the future problem to solve.”

**A variety of resource gaps were described as a significant barrier in several contexts.** One of the main barriers described in most countries was the **vertical programs** and systems not being accessible, inability of current IT infrastructure to harmonize different surveillance systems, and that IT solutions would need to be developed for integration to be possible. Over the course of the COVID-19 pandemic, there was a heavy reliance on laboratory and diagnostic capacity in all countries. This revealed the need to strengthen capacities in physical infrastructure, transport, equipment and supplies, and human resources, at both national and subnational levels, to activate the appropriate response efforts rapidly. In some contexts, for example in the UK, Pakistan, Uganda and Mozambique, additional resource gaps persist, such as a limited workforce in data analytics and interpretation; lack of training and continuous professional development for improving skills and capacities; and insufficient software and hardware e.g., computers, connectivity. Additionally, in the UK, one interviewee commented on the need to automate data processing and move away from manual methods of data collection and analysis, which leads to inefficiencies. Interviewees in Sweden and the UK further commented on the need to be more efficient in the allocation of resources to collect data and that, during the pandemic, there was an excessive amount of data collected that wasn’t feasible for public health or healthcare workers to analyze and interpret.

#### **4.2.4 Objective 3(b): Facilitators influencing the operationalization of the IDS system**

**A key facilitator that emerged was trust; between the population and the public health authorities, as well as between the different levels of public health authorities within countries; and with other sectors.** Trust between authorities often came hand-in-hand with a history of working collaboratively together and establishing open lines of communication and dialogue, which contributed toward strong working relationships. In Canada, interviewees repeatedly stated that data sharing between the provinces and territories and the national government could only succeed through trust between the various levels. Trust and the strength of professional relationships mediated the absence of any formal system or mechanism for sharing information and data. However, this could also be viewed as a barrier, since the accessibility of data relies on individuals and

interpersonal relationships (less permanent), rather than institutionalized mechanisms (more permanent). As one interviewee in the UK said, it depends on “enthusiastic individuals” and “constructive enablers who are involved from the start”, emphasizing the importance of individual personalities rather than the institutional environment (which is lacking in most countries).

**In most countries, the COVID-19 pandemic in fact helped to reveal gaps in current surveillance systems and helped to resurrect surveillance activities at a national and subnational level.** The ways in which the pandemic acted as a facilitator (and barrier, in some instances) are further described in Box 1.

**Respondents from several countries commented on the availability of existing resources to conduct surveillance activities, which would serve as assets in an IDS system.** In Uganda and the UK, interviewees reflected on the expertise of the current workforce to analyze and report surveillance data. In Uganda, the Field Epidemiology and Laboratory Training Program (FELTP) and the One Health Institute Fellowship help to provide a strong pool of epidemiologists to support surveillance activities. Similarly, in Pakistan, the FELTP and community-level Lady Health Worker programs are strengths that can be leveraged. However, in several countries, including Mozambique, Sweden, and the UK, interviewees reflected on the need to strengthen expertise in data visualization and translation of data for decision-making. In Canada, the Canadian Network for Public Health Intelligence (CNPHI) and the Global Public Health Intelligence Network (GPHIN) were consistently flagged as a facilitator owing to the well-established networks both domestically and internationally as well as the existing IT platform for CNPHI in particular.

#### **Box 1. Impact of the COVID-19 pandemic for an IDS system**

The COVID-19 pandemic helped to identify key areas of strength and weakness in current surveillance systems, serving at times as both a barrier and a facilitator to the integration of surveillance data. The major barriers and facilitators highlighted by interviewees are described below.

##### Barriers:

- There has been a high level of investment in the COVID-19 response at the expense of other priority pathogens where **surveillance has been interrupted** (Uganda, Pakistan, Malawi, Mozambique)
- The **mis- and disinformation surrounding the pandemic** has placed public health agencies at the center of increased government and public scrutiny (Canada).
- Later in the pandemic, COVID-19 became a barrier to people **visiting the health facility** and seeking appropriate care (Malawi).

Facilitators:

- Although political will and commitment to IDS has been lacking overall, the pandemic did **shift some political attention** toward the need for enhanced disease surveillance, and helped in educating key decision-makers on the importance and value of good quality surveillance information (Uganda, Pakistan, UK).
- The urgency and magnitude of the pandemic helped to **emphasize the role of the NPHI and resurrect surveillance activities** at subnational levels of the public health system, making subnational public health authorities more alert and sensitive to disease threats (Uganda, Pakistan).
- **Networks, relationships, and channels of cross-sector communication** that were established during the pandemic, and were invaluable during this time, have been maintained and has helped coordinate activities (such as data sharing) between stakeholders (Sweden, Uganda, Pakistan, Canada, Malawi).
- The pandemic helped the public health sector **acquire equipment, including IT equipment, as well as funding**, and spurred innovation in electronic surveillance systems (Uganda, Pakistan, UK, Canada).
- The pandemic **increased the public / community awareness and media attention** toward surveillance and public health activities (Canada, Malawi).

Table 3. Summary of the main barriers and facilitators common across countries

Theme	Common barriers	Common facilitators
Common understanding of IDS	<ul style="list-style-type: none"> <li>• Lack of a shared understanding of what IDS is, and how it might benefit from differing across countries</li> <li>• Low motivation to share data and limited awareness of its value</li> </ul>	
Governance and legal environment	<ul style="list-style-type: none"> <li>• No overarching system: surveillance is fragmented, not interoperable, or multiple parallel systems</li> <li>• Insufficient ownership of IDS and legislation for data sharing</li> </ul>	<ul style="list-style-type: none"> <li>• Strong and committed leadership to IDS</li> <li>• Legal agreements provide the basis for good cooperation (also under Relationship theme)</li> <li>• Existing international networks and guidance (e.g., WHO HUB, Global Public Health Intelligence Network)</li> </ul>
Relationships	<ul style="list-style-type: none"> <li>• Informal mechanisms for sharing (also a facilitator, but needs to be institutionalized)</li> </ul>	<ul style="list-style-type: none"> <li>• Strong relationships and trust identified as important</li> </ul>

		<ul style="list-style-type: none"> <li>• Strong dialogue between policymakers and public health officials</li> </ul>
Financing	<ul style="list-style-type: none"> <li>• Fragmented funding structures for development of and sustaining disease surveillance</li> <li>• Insufficient financing: multiple external donors create challenges for coordination, access to data and ownership</li> </ul>	<ul style="list-style-type: none"> <li>• Financing is increasingly targeted and available for specific actions</li> </ul>
Infrastructure	<ul style="list-style-type: none"> <li>• Public laboratories require skilled staff, equipment and supplies to sustain functionality</li> <li>• Private healthcare providers and laboratories need to be included</li> <li>• Data quality issues and gaps in resources for validating, interpreting, and analyzing data, limits translation of data into action; a lot of data processing is still manual and inefficient; limited tech</li> </ul>	<ul style="list-style-type: none"> <li>• Essential initial infrastructure already exists (e.g., laboratories, FETP training program, One Health working group, genome sequencing) that can be strengthened</li> </ul>

#### 4.2.5 Objective 4: Role of NPHIs in relation to other key stakeholders in central surveillance coordination and decision-making

Compared to the other objectives, this objective was less well explored and covered. Where insights were available, interviewees across many deep dive countries agreed that NPHIs should have a leadership role in implementing and coordinating surveillance activities and convening stakeholders from across different human/public health, animal health, and environment sectors, as well as across the public and private sectors, and from a national to subnational level. The active role played by NPHIs was implicit in responses. Common roles currently being played by NPHIs, to varying degrees of success, include coordination across different sectors and regions; acting as a reference laboratory; being the International Health Regulations (IHR) focal point; supporting training of workforce for surveillance; and issuing of public health advisories.

Although the role of the NPHI might be agreed in theory, in practice there are several important challenges highlighted by interviewees that need to be resolved for NPHIs to assume this role in **surveillance**. In the UK, for instance, interviewees described the current NPHI (UKHSA) within England as lacking the authority to influence data collection, analysis and reporting from the different devolved nations and different surveillance systems. The UKHSA can provide guidance but does not have the authority required to mandate a change in the system. Similarly, in Pakistan, the NPHI's (NIH) central role in coordination and decision-making is hampered by the system of devolved governance, which gives autonomy to provinces to determine how to organize and manage public health activities.

To strengthen the role of NPHIs in surveillance activities, two solutions were proposed: 1) systematic documentation of positive experiences and best practices; and 2) evaluate the

**feasibility of new or alternative governance models that can accommodate federal or devolved systems while still supporting the NPHI's central role.** On the first solution, interviewees from Mozambique suggested that systematic sharing of positive experiences and best practices from other countries in promoting NPHIs as leaders in surveillance would be helpful in understanding different approaches to charting this path forwards. On the second solution, interviewees from Pakistan commended the National Command and Operation Centre, which was set up during the COVID-19 pandemic, to establish coordination between the federal level, provinces, and international agencies, and proposed it as a model moving forwards with IDS. Interviewees also suggested establishing a "mini" NPHI in each province, which may seek leadership and expertise from the national-level NPHI.

#### **4.2.6 Objective 5: Key stakeholders' ideas on how to move forward and improve IDS**

Across the deep dive countries, there were several common priorities that emerged as key areas for moving forward. These priorities focused on:

- i. Establishing a common understanding of IDS purpose
- ii. Optimizing the governance and legal environment for integration
- iii. Formalizing collaborations between sectors, systems, and key stakeholders
- iv. Streamlining data processing functions
- v. Investing in a surveillance workforce including continuous training and development

The impression from the four LMIC reports suggest that definition of IDS per se was not really important to them. The concept of IDS and the WHO-defined IDSR strategy were effectively synonymous. For the high-income countries studied, many were not familiar with the IDS/IDSR terminology but understood the concept of and need for integration of disease surveillance systems. For all countries studied, what was key was the need for clarification and understanding of the purpose for the organization and functioning of the system.

How the systems are governed, including data protection and privacy concerns, as well as the presence of supportive legislation were also key enablers. The system was also far more organic and complex, involving the interaction of many different sectors, agencies, systems, and stakeholders. How they networked and interfaced, was another enabler and respondents valued trusted relationships.

All participating countries acknowledged the need to improve and streamline data processing functions, even in more established surveillance systems there was room for improvement and efficiency gains.

Finally, all countries acknowledged the workforce dimension, both in terms of skills, and capacity, as well as the need for ongoing training and development.

Based on the policy and practice implications, Figure 2 conceptualizes a five-step pathway for NPHIs to consider adapting to their specific context and needs. The pathway addresses some of the major barriers identified through this process, namely the lack of understanding of an IDS system in terms of what it would entail, the extent to which systems would be integrated, and the overall value-add of integration; as well as the political and financial barriers limiting efforts to advance or transition to an integrated system. The first step is dynamic in nature, recognizing that the process of clarifying what needs to be integrated and building an operational definition of IDS in the second step is iterative.

Where the funding is externally driven, integration needs to be built into a national strategic approach to effectively support the development of stronger national systems that serve broader surveillance needs, rather than just disease specific surveillance needs. However, there is also acknowledgement that where funding is conditional on demonstrating impact and results, efforts to integrated disease surveillance systems need to protect the quality of data generated if the process of integration is not to undermine the funding of the system.

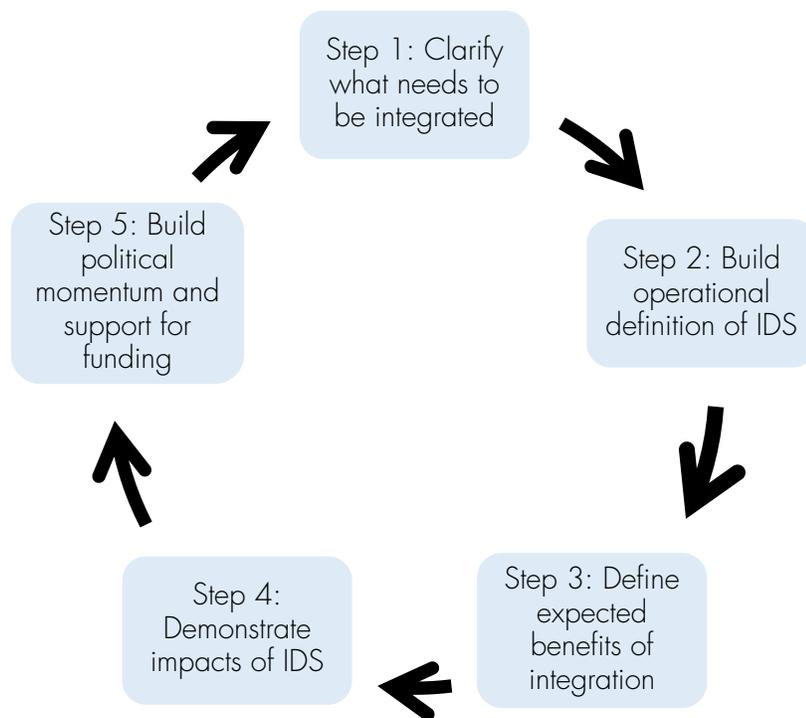


Figure 2. Five conceptual steps to address some of the major barriers in operationalizing IDS

In the Recommendations section of this report, we further build upon these key areas to offer five high-level recommendations and specific objectives that can be actioned.

## 5. RECOMMENDATIONS

We offer six higher-level recommendations that come out of this synthesis of the deep dives, as well as more specific objectives that can be implemented and are required before recommendations can be achieved. These objectives align with the overarching issues identified in Objective 1 and based on the individual country deep dive reports.

1. **The purpose of IDS should be both clarified and detailed to include clear objectives and expected outcomes of such a function (that enables data analysis of key surveillance data from different surveillance systems.)**
  - 1.1. Purpose needs to be defined and driven through targeted outcomes, based on country context. To enable ownership and commitment to a common goal for surveillance, whether it be for pandemic and epidemic surveillance, or to monitor disease trends and evaluate public health programs, the intended outcomes need to be agreed with from a multi-sectoral perspective.
  - 1.2. To achieve its intended purpose, an outline of the standard key components of the IDS system should be defined but be adaptable enough to conform with different country contexts based on their domestic characteristics. This may be determined after additional evidence generation, which may include a review of current IDS best practices.
  - 1.3. A guiding IDS purpose should first outline the objective of the integrated systems, and include which systems (e.g., active, passive, event-based, private), and even which categories of data within the systems, will be included in an integrated infrastructure and how the resulting data can be coordinated, analyzed, and used for decision-making and response activities to achieve the intended purpose.
  - 1.4. It should also be clear that integration does not start with programs but with people and roles, departments, and sectors that will have to implement integration of efforts first. The 'people' element of integration will include integrated training, workforce development, and work activities.
  - 1.5. Following a general but nuanced definition of the purpose of integration, countries should refine integration objectives to reflect national priorities, surveillance realities as well as ambitions, further the roles and expectation of implementation entities must be outlined in country integration definitions – especially the role of NPHIs in IDS stewardship.

- 1.6. There is a need to widen the scope to include other conditions of public health importance, such as incorporating the One Health aspects for early warning and collaborative surveillance.
2. **Strengthen domestic workforce for disease surveillance through formalized networks within and beyond health**
  - 2.1. Invest in and formalize stakeholder relationships across disciplines, networks, and communities of practice, such that collaborations are institutionalized – this will expand individual and interpersonal connections to institutional relationships. This should also be incorporated between different levels of government.
  - 2.2. Extend the process of formalizing collaborations to development partners and international entities to ensure that external funding and collaboration supports the domestic priorities.
  - 2.3. Develop privacy agreements, roles and responsibilities, and memoranda of understanding to facilitate roles and responsibilities and data ownership, especially between national and subnational entities.
  - 2.4. Reinforce and encourage participation in existing domestic and international data sharing platforms.
3. **Facilitate learning and domain expertise through training and workforce development**
  - 3.1. Specialized functions should be invested in throughout the workforce pipeline, including working with educational facilities and other organizations (that provide degrees and/or competency-based training), to ensure adequate numbers are well positioned to fill surveillance, data management, and laboratory roles within the countries; but also by investing in a specialized workforce (such as through the Field Epidemiology Training Program and the broader public health workforce) that can process, analyze, and interpret integrated surveillance data and be utilized across disease or sector needs.
  - 3.2. Workforce planning is needed to anticipate the number of staff and scope of skillsets required to maintain and develop IDS.
  - 3.3. At the level of data collection and analysis, provide comprehensive training of key focal points on various aspects of IDS from data generation to consolidation; continuous tandem training of data collectors, data entry and analysis individuals should occur to ensure standardization of terms and unified understanding of objectives.
  - 3.4. Promote not just within-country learning, but also peer-to-peer learning between countries, sharing good practice and creating opportunities for greater harmonization of surveillance activities.

4. **Ensure that resources reflect the sustained investment needs and sufficient levels of funding required to catalyze systems integration and bolster coordination efforts needed, not only during emergencies but also for daily operation of integrated surveillance**
  - 4.1. A costing study or cost analysis may be required to identify funding needs for every element of IDS and provide costing estimates that must be considered when funding IDS, both at implementation stage as well as for sustaining functions in the longer term.
  - 4.2. In countries that had surplus donor or domestic funding during the COVID-19 pandemic, funding levels and associated activities and outcomes should be reassessed and considered – annual funding estimates should reflect resilient system requirements.
  - 4.3. Funding streams for vertical programs from external donors needs to be considered and active dialogue with donors needs to be undertaken to find solutions that do not disrupt the foundational strengthening of IDS and associated functions.
  - 4.4. National priorities need to set and shape the evolution of surveillance systems that external funding partners need to recognize and respect the competing demand on surveillance systems. This requires donors to invest to maximize the efficient future development of systems to meet essential surveillance needs, not just disease specific needs.
  
5. **Build an environment of data and system interoperability throughout every level and across sectors to serve the country's integration objectives**
  - 5.1. Harmonize overarching IT infrastructure – working with specialist IT agencies and solutions architects with the right expertise – to support streamlining of data processing, which should include uniform tools and data flow mechanisms at both national and subnational levels. Advances in data processing should be paired with expertise to allow for accurate interpretation and decision-making from the increased outputs.
  - 5.2. Systems, including surveillance system/s and functions, have both technological (hard) and socio-political (soft) elements. It is essential to give due attention to the soft elements required for integration, such as trust and communication between stakeholders, sufficient clarity among politically powerful stakeholders on the benefits from investing in IDS and addressing concerns about negative consequences of sharing data among vertical programs and private sector providers. This will require investing in relationships continuously and intensifying advocacy efforts for the integration that is needed.
  - 5.3. Systematically and regularly streamline data inputs by examining systems for duplication and redundancy and, by evaluating utility of new data sources that have been generated because of the COVID-19 pandemic or other health emergencies.
  - 5.4. Build space for non-government actors, civil society, and communities to input and participate in surveillance and monitoring structures.

6. **Strengthen the role of NPHIs/Public Health entities:** NPHIs and where they are not established, public health entities, are at the interface of different sectors and can create links and partnerships for shared intelligence where we can create consensus and reduce duplication. NPHIs being at the center, as a trusted partner, brings health and non-health sectors together and acts as a catalyst for evidence-based decisions that are needed to tackle harmful impacts on health and well-being. They can build both tacit and explicit collaboration and partnerships across sectors.
  - 6.1. NPHIs often are, and should be, a key component of national structures. They can provide the institutional context that builds, protects and champions the effective collection and analysis of data to inform policy and respond to disease threats. The importance of legal authorities to share and analyze data across levels of public health system, especially in federal systems was highlighted. NPHIs' and other public health entities' legal mandates and functions should be strengthened to enable multi-sectoral data capture and validation, data analysis, and translation into evidence that enables action and response to emerging pandemics and epidemics.
  - 6.2. NPHIs and public health entities bridge sectoral divides, drawing on professional networks, peer-to-peer linkages and trusted relationships, to overcome barriers to data sharing. They can generate the evidence, develop approaches and protocols and SOPs that can strengthen surveillance systems and identify and define the skills and competencies needed by the public health workforce (including multi-sectoral skills) to support strengthened surveillance. Inter-professional and multi-disciplinary research and innovation should be supported through financing models supporting cross-cutting themes for research and innovation.

## 6. SUMMARY

The deep dives corroborate findings from the survey workstream and highlight specific insights and understanding within specific national contexts.

The importance of interpersonal relationships, networks, information governance and legal agreements for facilitating data sharing was highlighted. It is important to also consider integration of public and private surveillance systems, especially in countries where a substantial proportion of healthcare is through private providers.

Some of the LMICs reported lacking a coherent legal framework that addresses the various aspects of IDS. This is reflected in the national governance of IDS. Although the MOH often plays a major role for human health, and ministries of animal health or agriculture are responsible for animal health and food safety, the responsibility within a ministry can be split between departments. The deep dives also revealed a lack of strategy or clear instruction from the central authority. Weak communication between central stakeholders, the lack of political awareness and support, and a lack of clear support to and allocation of power to the NPHI was also noted.

Similar to the situation with LMICs, the deep dives in HICs demonstrated the importance of a legal basis and mandate for surveillance. A legal framework helps to articulate the roles of the different actors in the system. Laws and other regulations facilitate surveillance by mandating groups to report and provides legal instrument for sharing of data. Data collection can be steered by laws and regulations. Where there was a lack of clarity on responsibilities between agencies, this can result in gaps in governance and a poorer response.

Most of the core elements for a good IDS are in place, but there is room for improvement in many areas. These include areas of governance, guidelines, human resources, funding, data quality, digitization for example include:

### Governance

- The **legal framework** is deficient in several countries, mostly lacking a clear purpose, and lacking a clear assignment of responsibility for the totality of IDS.
- As a result, the countries experience **fragmented ownership** of surveillance in government, not being placed with one agency. The NPHI is a good choice for placing such a responsibility.

- There is varying **political commitment** to IDS, although this improved with the COVID-19 pandemic when many stakeholders experienced the need for good surveillance data. Strong national leadership is needed.
- **External funding** of disease programs with surveillance systems is critical for donor dependent countries. However, they cause fragmentation of the disease surveillance and exert undue influence – although unofficially– on important decisions.

### Guidelines

- The **IDSR technical guidelines** developed by WHO AFRO have been important for the development of disease surveillance in countries in Africa and beyond. The guidelines are comprehensive and ambitious, and its 3<sup>rd</sup> edition comprises ca. 500 pages. The guidelines need to be better adapted to national settings and resources to be better suited for national implementation.
- **Case definitions**, tools, protocols, and SOPs need to be better coordinated nationally (and adhere with international standards), implemented, and taught.

### Human resources

- There is a **lack of trained staff**, with availability somewhat better at national level than district and local levels. **Data collectors at facility** sites are the most critical factor.
- **FETP** and other training programmes are important.

Local knowledge, **networks**, relationships, and trust are important

### Integrated Disease Surveillance – IDS

- In countries that have implemented **IDSR**, it is often seen as the same as IDS.
- Integration is perceived as synchronizing or better coordinating IDSR communicable diseases with **vertical, donor driven programs**.
- **Improving integration** of aggregate data from health facilities with lab data, and better collaboration between human and animal health (One-health) is challenging.
- **Good quality CRVS** is often missing in LMICs.

### Data quality

- Disease surveillance registries often have **poor data quality**.
- **Laboratory confirmation of cases** are often missing. Laboratories need to be strengthened and data fed into IDSR.

There is a great need to **improve data collection, validation**, analysis, interpretation, and reporting at all levels.

### Digitization

- In LMICs, most patient **records are on paper**, and there is a gradual, but slow introduction of electronic medical records.
- Most countries aim to have **one electronic system** where data can be transferred from different sources.
- There are **challenges in data transfer** and weakness and instability in electronic transfers, leading to duplications in sending both electronic and paper reports.

### Funding

- Most disease surveillance systems in LMICs are underfunded with regards to human resources, technical systems (e.g., IT-software development), and microbiological laboratories
- External support from **international donors was critically important** to develop and run systems. But many of them **fragment and duplicate national surveillance** and **drain human resources** from NPHIs.

The synthesis identified five overarching issues to establishing IDS systems: there is a lack of clarity in terms of the **purpose and value** of an IDS system that unites different stakeholders and sectors at a national level; the **ownership** of an IDS system is unclear, and there is a perceived **absence of motivation** to manage a change in surveillance practices (in part due to a lack of systems and structures that would enable such integration across stakeholders and sectors); the **legal environment** poses significant challenges to facilitating information and data sharing within and across agencies; existing **IT technology and infrastructure** used by different stakeholders and sectors are incompatible with one another; and finally, there are significant gaps in **funding and investment** in integration.

The resulting six recommendations align with these themes:

1. The purpose of IDS should be both clarified and detailed to include clear objectives, essential functions and expected outcomes of such a system.
2. Strengthen domestic workforce for disease surveillance through formalized networks within and beyond health. Strengthen human resource capabilities by formalizing networks and reinforcing the workforce.
3. Facilitate learning and domain expertise through training and workforce development.
4. Ensure that resources reflect the sustained investment needs and sufficient levels of funding required to catalyze systems integration and bolster coordination efforts needed, not only during emergencies but also for daily operation of integrated surveillance.
5. Build an environment of data and system interoperability throughout every level and across sectors to serve the country's integration objectives.

6. Strengthen NPHIs and other Public Health entities; NPHIs being at the center, as a trusted partner, brings health and non-health sectors together and acts as a catalyst for evidence-based decisions.

While some additional evidence is needed to inform these recommendations and transform them into actionable steps appropriate for the different country contexts, the synthesis from this deep dive provides direction to help NPHIs steer system development to further progress IDS within their countries.

## 7. ACKNOWLEDGEMENTS

We thank the following members of the IDS deep dive working group, the teams of country working groups, their organizations and all other contributors for sharing their generous time and valued expertise to complete this work:

Professor Andrew Lee, University of Sheffield and UK Health Security Agency  
Ms. Sadaf Lynes, International Association National Public Health Institutes  
Dr. Vicky Ng, Public Health Agency Canada (PHAC)  
Dr. Celine Nadon, PHAC  
Ms. Angela Hinds, Caribbean Public Health Agency (CARPHA)  
Dr. Lisa Indar, CARPHA  
Ms. Patricia Smith-Cummings, CARPHA  
Dr. Stephanie Salyer, Africa Center for Disease Control and Prevention (Africa CDC)  
Ms. Maryam Buba, Africa CDC  
Dr. Veronica Briesemeister, Robert Koch Institute (RKI)

We would like to thank the Evaluation and Analysis team:

Ms Afifah Rahman-Shepherd, Saw Swee Hock School of Public Health, National University of Singapore, and Afifah RS Consulting  
Dr Ngozi Erundu, O'Neill Institute for National and Global Health Law, Georgetown University  
Dr Mishal Khan, London School of Hygiene and Tropical Medicine

To the Deep Dive In-Country Teams and peer NPHIs, without which this project would not have been possible:

### **Malawi working group**

Dr. Benson Chilima, Public Health Institute Malawi (PHIM)  
Dr. Annie Chauma, PHIM  
Dr. Mtisunge Yelewa, PHIM  
Dr. Noel Khunga, PHIM  
Dr. Dzinkambane Kambalame, PHIM  
Dr. Edward Chado, PHIM

### **Partner NPHI**

Dr. Bjorn Iversen, Norwegian Institute of Public Health (NIPH)  
Dr. Trude Arnesen, NIPH

Dr. Emily MacDonald, NIPH  
Dr. Karine Nordstrand, NIPH

### **Mozambique working group**

Dr. Eduardo Samo Gudo, National Institute of Health - Ministry of Health Mozambique (NIH-MOH)  
Mozambique

Dr. Sergio Chicumbe, NIH-MOH Mozambique  
Dr. Ivalda Macicame, NIH-MOH Mozambique  
Dr. Didier Mugabe, NIH-MOH Mozambique  
Dr. Jose Paulo, NIH-MOH Mozambique  
Dr. Tatiana Marufo, NIH-MOH Mozambique  
Dr. Etelvina Mbalane, NIH-MOH Mozambique  
Dr. Thandie Harris, NIH-MOH Mozambique  
Dr. Sergio Chicumbe, NIH-MOH Mozambique  
Dr. Janet Dula, NIH-MOH Mozambique  
Dr. Liliana Baloi, NIH-MOH Mozambique  
Dr. Americo Barata, National Institute of Health - Nampula  
Dr. Edna Viegas, National Institute of Health - Maputo City  
Dr. Lutero Cuamba, NIH-MOH Mozambique  
Dr. Acacio Sabonete, NIH-MOH Mozambique  
Dr. Naisa Manafe, NIH-MOH Mozambique  
Dr. Nilsa Nascimento, NIH-MOH Mozambique

### **Partner NPHI**

Dr. Anders Tegnell, Public Health Agency Sweden (PHAS)  
Dr. Charlotte Larsson Sandén, PHAS  
Dr. Maria Axelsson, PHAS

### **Pakistan working group**

Mr. Muhammad Adeel Khan, Tech-National Institute of Health (NIH) Pakistan  
Mr. Muhammad Ans Shams, Tech-NIH  
Mr. Mustafa Chaudry, Tech-NIH

### **Partner NPHI**

Dr. Muhammad Sartaj, United Kingdom Health Security Agency (UKHSA)  
Dr. Anne Wilson, UKHSA  
Dr. Muhammad Asif Khan, UKHSA  
Ms. Nadia Nisar, UKHSA  
Dr. Najma Javed Awan, UKHSA  
Dr. Syed Wasif Shah, UKHSA

### **Uganda working group**

Dr. Alex Ario Rioplexus, Uganda National Institute of Public Health (UNIPH)

Dr. Felix Ocom, UNIPH

Dr. Petranilla Nakamya, UNIPH

Dr. Robert Zavuga, UNIPH

Dr. Immaculate Atuhaire, UNIPH

Dr. Alice Asio, UNIPH

Dr. Vento Auma, UNIPH

Dr. Hilda Wesonga, UNIPH

Dr. Maria Gorreti Zalwango, UNIPH

Dr. Brenda Simbwa Nakafero, UNIPH

Dr. Mercy Wendy Wanyana, UNIPH

Dr. Jane Frances Zalwango, UNIPH

### **Partner NPHI**

Ms. Erika Meyer, U.S. CDC

Ms. Briana Lucido, U.S. CDC

### **Canada working group**

Dr. Dana Paquette, Public Health Agency of Canada (PHAC)

Ms. Jessica Deming, PHAC

Dr. Ayesha Siddiqua, PHAC

Ms. Emily-Ann Butler, PHAC

Ms. Orsolya Gyorgy, PHAC

Dr. Jean-Claude Mutabazi, PHAC

Ms. Janis Ellis-Claypool, PHAC

Dr. Celine Nadon, PHAC

Dr. Victoria Ng, PHAC

Dr. Eleni Galanis, PHAC

Ms. Ranu Sharma, PHAC

Ms. Delane Boakye, PHAC

Dr. Erin Rees, PHAC

### **Partner NPHI**

Dr. Sally MacVinish, UKHSA

### **Sweden working group**

Dr. Anders Tegnell, Public Health Agency Sweden (PHAS)

Dr. Charlotte Larsson Sandén, PHAS

Dr. Maria Axelsson, PHAS

Dr. Karolina Fischerström, PHAS

Dr. Amanda Ternstedt, PHAS

Dr. Sonja Löfmark, PHAS

Dr. Thomas Åkerlund, PHAS

Dr. Emmy Johdet, PHAS

Dr. Annelie Sandén, PHAS

#### **Partner NPHI**

Dr. Astrid Louise Løvlie, Norwegian Institute of Public Health (NIPH)

Dr. Elina Marjukka Seppälä, NIPH

Dr. Karine Nordstrand, NIPH

#### **UK - England working group**

Professor Andrew Lee, University of Sheffield - UKHSA

Dr. Sally MacVinish, UKHSA

Ms. Jennifer Willburn, UKHSA

Ms. Hannah Watson, UKHSA

#### **Partner NPHI**

Dr. Celine Nadon, PHAC

Finally, the guidance and expertise of the IDS Executive Committee and IDS Technical Committee has been critical throughout this project.

Committee / Working Group	Members	Organization
<b>Executive Committee</b>		
Chair	Dr. Quentin Sandifer	IANPHI
Members	Dr. Kip Baggett	US Center for Disease Control and Prevention
	Dr. Geneviève Chêne	Santé publique France (SPF)
	Dr. Scott Dowell	Bill and Melinda Gates Foundation (BMGF)
	Dr. Angela Fehr	Robert Koch Institute (RKI)
	Dr. Meerjady Sabrina Flora	IANPHI-Ministry of Health, Bangladesh
	Dr. Eleni Galanis	Public Health Agency Canada (PHA-Canada)
	Engr. Pierre Grand	WHO Hub-Pandemic and Epidemic Surveillance, Berlin
	Professor Laetitia Huiart	Santé publique France
	Dr. Bjorn Iversen	Norwegian Institute of Public Health (NIPH)
	Dr. Maarit Kokki	Europe CDC

	Professor Andrew Lee	UKHSA, University of Sheffield, UK
	Ms. Sadaf Lynes	IANPHI
	Dr. Natalie Mayet	National Institute For Communicable Diseases of South Africa (NICD)
	Dr. Lenka Korner Nahodilova	Robert Koch Institute (RKI)
	Dr. Patrick O'Carroll	Taskforce for Global Health
	Professor Neil Squires	UK Health Security Agency (UKHSA)
	Dr. Joy St John	Caribbean Public Health Agency (CARPHA)
	Dr. Raji Tajuddin	Africa Center for Disease Control
	Dr. Anne-Catherine Viso	IANPHI
	Dr. Ellen Whitney	IANPHI-Emory University

### Technical Committee

Chair	Professor Neil Squires	UKHSA
Members	Ms. Malin Ahrne	Public Health Agency, Sweden
	Dr. Alex Riolexus Ario	Uganda NPHI
	Dr. Veronica Breisemeister	RKI
	Dr. Annette Cassy	Mozambique
	Dr. Osman Dar	UK Health Security Agency (UKHSA)
	Dr. Jean-Claude Desenclos	Santé publique France
	Dr. Kathy Gallagher	US CDC
	Dr. Eduardo Samo Gudo	National Institute of Health-Ministry of Health, Mozambique
	Professor Laetitia Huiart	Santé publique France
	Dr. Lisa Indar	Caribbean Public Health Agency (CARPHA)
	Dr. Bjorn Iversen	Norwegian Institute of Public Health (NIPH)
	Dr. Ilesh Jani	Mozambique, NPHI
	Dr. Muhammad Khan	NIH, Pakistan
	Professor Andrew Lee	University of Sheffield
	Ms. Sadaf Lynes	IANPHI
	Dr. Carlos Martinez	RKI
	Dr. Robert Otok	Association of Schools of Public Health in the European Region (ASPHER)
	Dr. Dana Paquette	Public Health Agency Canada
	Dr. Claudia Perandonnes	IANPHI
	Dr. Carl Reddy	Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET)
	Dr. Anders Tegnell	Public Health Agency, Sweden
	Ms. Kyeng Mercy Tetuh	Africa CDC

	Dr. Sabrina Weiss	Robert Koch Institute (RKI)
--	-------------------	-----------------------------

## REFERENCES

1. Nsubuga P, White ME, Thacker SB, et al. Public Health Surveillance: A Tool for Targeting and Monitoring Interventions. In: Jamison DT, Breman JG, Measham AR, et al., editors. Disease Control Priorities in Developing Countries. 2nd edition. Washington (DC): The International Bank for Reconstruction and Development / The World Bank; 2006. Chapter 53. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK11770/> Co-published by Oxford University Press, New York.
2. World Health Organization. Regional Office for Africa Integrated disease surveillance strategy, a regional strategy for communicable diseases 1999–2003. Harare: World Health Organization Regional Office for Africa. 1999.

# APPENDICES

## APPENDIX 1

Thematic areas covered in the focus group discussions and semi-structured interviews

Objectives of the deep dives	Proposed areas to be covered by the deep dives
<p>1. Explore participants' understanding of current surveillance systems and the extent to which IDS systems have been developed in the country</p>	<ul style="list-style-type: none"> <li>● Who are the key stakeholders in current surveillance systems and to what extent do they cooperate/coordinate on data-sharing</li> <li>● Major components of any existing IDS system and the perceived gaps in IDS</li> <li>● Whether new areas of focus for surveillance or initiatives have resulted from the COVID-19 pandemic and whether that is shaping approaches and collaboration on surveillance</li> </ul>
<p>2. Understand types of surveillance programs in the country, including how they have been implemented and integrated at national level</p>	<ul style="list-style-type: none"> <li>● Types of surveillance programs (notifiable disease and other Disease surveillance or pathogen surveillance systems, including sequencing, sewage and septic surveillance, population immunity surveillance and vaccine effectiveness, etc.)</li> <li>● What efforts have been made to promote integration?</li> <li>● What are the barriers and enabling factors to achieve this?</li> </ul>
<p>3. Explore factors (barriers and facilitators) influencing the operationalization of the IDS system</p>	<ul style="list-style-type: none"> <li>● Governance factors (leadership, accountability, national plan of action for IDS, regulations and enforcement)</li> <li>● Structural/system factors within relevant sectors (type of data currently collected, in which format incl. use of digital technology, how they are integrated)</li> <li>● Financing</li> <li>● Factors related to core functions (Detect, Report, Analyze, Investigate/confirm, Respond, Feedback, Evaluate, Preparedness)</li> <li>● Resourcing requirements (Human resources-workforce, training, supervision; Laboratory capacity, networks-incl. genomic analysis; Data-availability, transparency, interoperability, integration; Information technology; Other resources including SOPs, and guidelines)</li> </ul>

<p>4. Explore the role of NPHIs in relation to other key stakeholders in central surveillance coordination, and decision making</p>	<ul style="list-style-type: none"> <li>● Key functions of NPHI in the country, cross-border, regional and international relationships</li> <li>● NPHI's role in central surveillance coordination, decision making (incl. modelling, forecasting, and analytics) (incl. access to the private sectors' information)</li> <li>● Other key stakeholders in surveillance systems and the extent of cross-government or agency coordination and sharing of data</li> </ul>
<p>5. Explore key stakeholders' ideas on how to move forward and improve IDS</p>	<ul style="list-style-type: none"> <li>● IDS definition</li> <li>● Key areas for the development of the country's IDS system</li> <li>● IDS at the regional level, cross borders (if relevant)</li> <li>● Opportunities and challenges of moving this forward</li> </ul>

ANNEX 2: COUNTRY REPORTS (ATTACHED)

