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The state of integrated disease surveillance in seven countries: a synthesis report

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ABSTRACT

Objectives: Integrated disease surveillance (IDS) offers the potential for better use of surveillance data to guide responses to public health threats. However, the extent of IDS implementation worldwide is unknown. This study sought to understand how IDS is operationalized, identify implementation challenges and barriers, and identify opportunities for development.

Study design: Synthesis of qualitative studies undertaken in seven countries.

Methods: Thirty-four focus group discussions and 48 key informant interviews were undertaken in Pakistan, Mozambique, Malawi, Uganda, Sweden, Canada, and England, with data collection led by the respective national public health institutes. Data were thematically analysed using a conceptual framework that covered governance, system and structure, core functions, finance and resourcing requirements. Emerging themes were then synthesised across countries for comparisons.

Results: None of the countries studied had fully integrated surveillance systems. Surveillance was often fragmented, and the conceptualization of integration varied. Barriers and facilitators identified included: 1) the need for clarity of purpose to guide integration activities; 2) challenges arising from unclear or shared ownership; 3) incompatibility of existing IT systems and surveillance infrastructure; 4) workforce and skills requirements; 5) legal environment to facilitate data sharing between agencies; and 6) resourcing to drive integration. In countries dependent on external funding, the focus on single diseases limited integration and created parallel systems.

Conclusions: A plurality of surveillance systems exists globally with varying levels of maturity. While development of an international framework and standards are urgently needed to guide integration efforts, these must be tailored to country contexts and guided by their overarching purpose.

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Introduction

Disease surveillance is a vital component of effective public health systems that enables early detection and timely response to public health threats.[1] However, the COVID-19 pandemic exposed weaknesses in disease surveillance worldwide, resulting in heightened public and political attention to epidemic preparedness and response.[2] Improvements in disease surveillance systems and the broader context in which they operate are key to better informed and targeted public health decision-making.

The World Health Organization (WHO) has for decades advocated the adoption and implementation of the concept of integrated disease surveillance (IDS) to ensure efficient, effective and coordinated responses to disease outbreaks.[3] IDS is 'a combination of active and passive systems using a single infrastructure that gathers information about multiple diseases or behaviours of interest'.[4] However, in many countries, surveillance operates in silos with separate surveillance systems, each handling one disease or a group of diseases.[5] Coordination between these silos is often suboptimal, which means that surveillance resources are inefficiently utilised. The WHO IDS strategy sought to address this issue by making surveillance systems from different sources more useable and to help public health managers and decision-makers improve detection and response to the leading causes of illness, death, and disability.[6]

Despite the IDS concept having existed for over two decades, its implementation has been limited. Its operationalisation is challenging, and there is no universally agreed definition of IDS nor clear strategies on how it can be implemented in different settings.[7–9] Although the WHO African Region has endeavoured to implement IDS over the past decade, the extent of IDS implementation worldwide is unknown.[10] To address this gap, this qualitative study was undertaken in a select number of countries to understand how IDS is conceptualised, including challenges and opportunities for development and successful solutions to problems encountered. A secondary objective was to also examine the impact of the COVID-19 pandemic on the development of surveillance systems.

Methods

This study is part of a wider multicomponent programme funded by the Bill and Melinda Gates Foundation (BMGF) and delivered by the International Association of National Public Health Institutes (IANPHI) that sought to comprehensively understand the current state of IDS implementation globally and elucidate the evidence base for it. This article specifically focuses on one component, a synthesis of several qualitative studies conducted in seven countries: Canada, Malawi, Mozambique, Pakistan, Sweden, Uganda, and England (Supplementary file 1). The countries were purposefully selected to include perspectives from high-income countries (HICs) as well as lower- and middle-income countries (LMICs), across different world regions. The country studies were done jointly in a twinning partnership with another NPHI as part of efforts to share learning, and ensure objectivity in the data collection and analysis process. The *lead NPHI*-partner NPHI pairings were as follows: *Malawi*—Norway, *Mozambique*—Sweden, *Uganda*—US, *Pakistan*—England, *England*—Canada, *Canada*—England, and *Sweden*—Norway. This involved a representative from the partner NPHI supporting the approach, planning, data collection or analysis.

The country studies were undertaken between May and September 2022. A standardised data collection approach was developed and replicated across the seven countries. In each country, study teams were established by the participating NPHI to undertake data collection and initial analysis. Each country was set a target of completing a mix of 15 focus group discussions (FGDs) and key informant interviews (KIIs), which was considered sufficient to achieve data saturation.[11,12] To enhance standardisation, a training workshop was conducted remotely via webinar prior to data collection so that project leads and staff in each country were familiar with the study aims and methodology.

A standard topic guide and interview schedule (Supplementary files 2 and 3, respectively) for the FGDs and KIIs were devised, guided by a bespoke conceptual framework developed for the project (Fig. 1). The framework, based on the WHO IDS framework[13] and Morgan et al. (2021),[14] considers five domains required for an

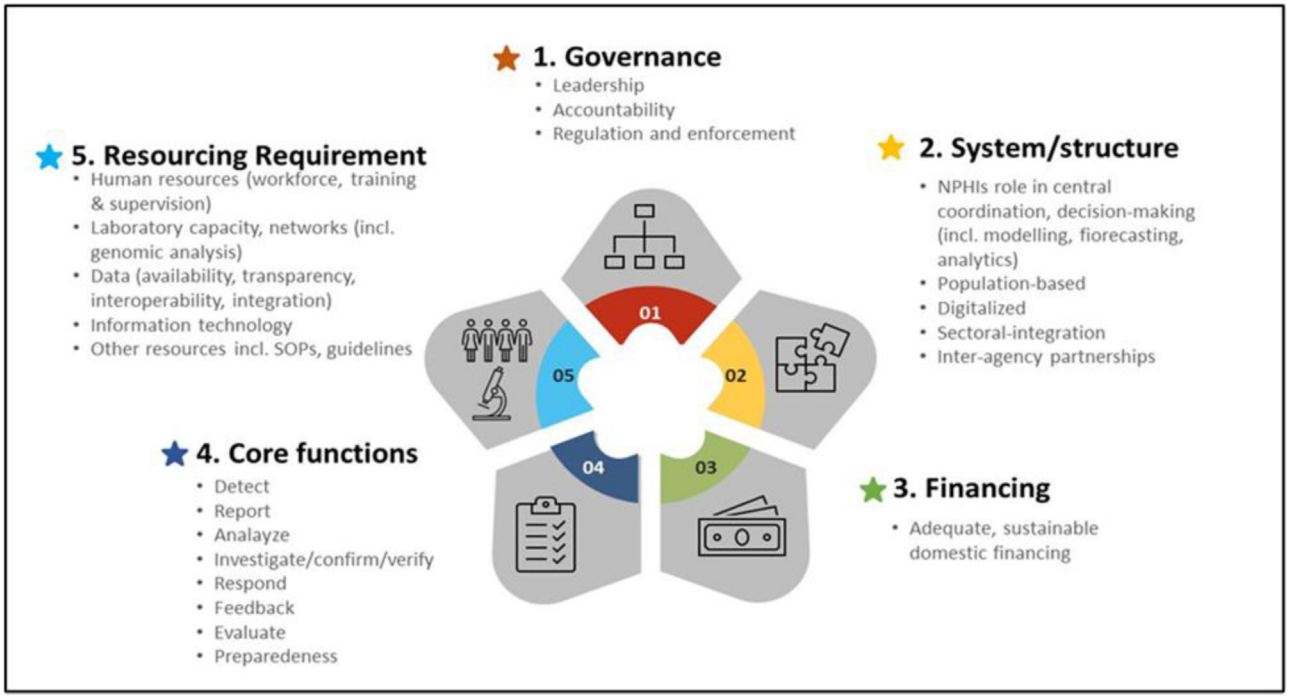

Fig. 1. Conceptual framework of IDS developed for the project.

integrated vision of disease surveillance from organisational and operational aspects: 1) governance, 2) system and structure, 3) financing, 4) core functions, and 5) resourcing requirements. Project teams had some flexibility to iteratively adapt questions to their country context and develop further subquestions to explore relevant emerging themes of interest. Topic guides were sense checked and piloted in Pakistan before being rolled out to other countries.

FGDs and KIIs took approximately an hour and were done remotely or face-to-face, subject to local practicalities and choice. The country study in England was done fully remotely by videoconferencing, whereas in Canada, it was conducted partly remotely using videoconferencing and partly face-to-face. In Sweden, a hybrid approach was used combining both in-person and online meetings with participants, whereas the country studies in Pakistan, Malawi, Mozambique and Uganda were carried out mostly in-person. Research teams in participating countries were instructed to conduct purposive sampling to recruit local participants from different administrative levels (national, provincial, and local), sectors (e.g., human health, animal health, environmental health, non-governmental organisations), and both urban and peripheral regions, in order to obtain a broad range of perspectives.

FGDs and KIIs were conducted in the local or national languages or in English. Each data collection team had one facilitator and one note-taker to take contemporaneous notes. FGDs and KIIs were voice-recorded with participants' permissions to facilitate completion of notetaking. Teams were briefed on good data management practices including issues of anonymity, confidentiality, and data security. They were also advised to be mindful of positionality bias in data collection due to their NPHI affiliation.

Throughout the data collection period, meetings were held weekly with country leads to share progress and discuss emerging findings. Local teams produced descriptive summaries of the FGDs and KIIs that were translated into English where necessary and a country report that summarised their findings. The FGD and KII summaries and country reports were thematically analysed by a central project team who then synthesised emergent themes across the countries.

The team adopted a deductive approach to analysis guided by the five domains of the conceptual framework outlined earlier. Microsoft Excel was used for data analysis. Data analysis and identification of themes ceased when thematic saturation was reached, and new data analysed did not shed further insights into what was already identified. Two group discussions were subsequently held with the data collection teams to sense-check, present and discuss key findings.

Table 1
Number of FGDs and KIIs conducted for the country studies in each country within timescale of the project.

Country	Number of FGDs	Number of KIIs
Canada	7	3
Malawi	6	9
Mozambique	2	5
Pakistan	4	8
Sweden	5	4
Uganda	5	9
England	5	10
Total	34	48

Results

In total, 34 FGDs and 48 KIIs (Table 1) were conducted in the seven countries. A total of 271 participants (98 national levels, 87 provincial or state or regional level and 86 district level and below) took part in the study (Table 2). Key results are presented below (also summarised in Table 3).

Participants' understanding of the state of IDS

None of the participating countries had a fully established integrated surveillance system. Disease surveillance was reported to be fragmented with multiple separate surveillance systems in existence. This affected how readily information could be accessed, analysed, interpreted, and disseminated. The integration of surveillance systems required the coordination of various stakeholders with diverse needs and agendas. Adequate representation and engagement from the different sectors involved in national surveillance activities was also needed. However, participants noted there was often insufficient multisectoral collaboration. Notably, there was no consistent understanding of IDS, both within and across different contexts, as IDS was conceptualised differently depending on context, sector, or stakeholder. Participants from HICs were generally unfamiliar with the term IDS. Consequently, the term IDS had to be paraphrased to 'integration of disease surveillance', which participants were able to engage with. An interesting observation from some countries was that during crises, an informal form of integration occurred. This was built on personal contacts between key stakeholders, which made it possible to collect data from many sources and establish a form of de facto integration.

Governance

Good governance, such as leadership, accountability, regulations and enforcement, was observed to be a prerequisite for operationalising IDS. The purpose and value of integration also needed to be clear. Participants from Uganda and Mozambique reported that some decision-makers did not understand the importance or value of surveillance. Participants in Pakistan and Uganda noted a general lack of motivation to report surveillance data and to provide the required information to the right stakeholders. Paradoxically, participants from Canada, Sweden and England gave examples of functioning surveillance systems able to integrate multiple sources of information to fulfil specific

Table 2
FGDs and KIIs participants' profiles at different health system level.

	National level	Provincial or state or regional level	District level and below	Total participants
Canada	24	12	0	36
Malawi	19	16	17	52
Mozambique	2	16	1	19
Pakistan	19	24	2	45
Sweden	16	13	9	38
Uganda	5	0	49	54
UK	13	6	8	27
Total	98	87	86	271

Table 3
Facilitators and barriers to the operationalization of IDS.

Conceptual framework domains	Identified facilitators	Identified barriers
Governance	Strong and committed leadership to IDS Legal agreements that provide the basis for good cooperation	Insufficient ownership of IDS and legislation for data sharing. Lack of a shared understanding of what IDS is.
Systems & Structures	Existing international networks and guidance (e.g. WHO HUB, Global Public Health Intelligence Network)	Lack of formal mechanisms for data sharing. Country context-specific models need to be developed looking at ground level facilitators and national level enablers. Barriers to implementation need to be recognised of a 'one size fits all' model.
Financing	Financing that is targeted and available for specific actions	Insufficient financing; multiple external donors create challenges for coordination, access to data and ownership. Fragmented funding structures for development and sustaining disease surveillance.
Core surveillance functions	Strong dialogue between policymakers and public health officials Strong relationships and trust between surveillance stakeholders	No overarching system exists; surveillance is fragmented, not interoperable, or multiple parallel systems. Low motivation to share data and limited awareness of its value. Private healthcare providers and laboratories are often not included.
Resourcing requirements	Essential initial infrastructure already exists (e.g., laboratories, FETP training program, One Health working group, genome sequencing) that can be strengthened	Public laboratories require skilled staff, equipment and supplies to sustain functionality Data quality issues and gaps in resources for validating, interpreting, and analysing data, that limits translation of data into action. A lot of data processing that is still manual and inefficient. Limited supporting technology.
Other emerging themes		Reactionary approach ("firefighting" after an outbreak), rather than preventative. COVID-19: Politicisation can distract attention and resources; and there was too much data.

surveillance functions that suggests that whilst integration is desirable, it may not be essential.

Another issue raised by participants was the lack of clarity as to who was responsible for integration. This has implications for ownership and leadership for integration, given the fragmentation and existence of multiple surveillance systems in countries. Participants in Mozambique and Uganda further commented on the need to clarify the governance and reporting structures for an integrated system as there can be confusion in roles and responsibilities between national and subnational surveillance systems.

Systems and structure

Many of the countries studied reported issues with incompatibility and limited interoperability of information technology (IT) systems. This led to problems with ensuring the quality (e.g., reliability, accuracy) and integrity (e.g., completeness, consistency, context) of data when merged. Integration and interoperability issues across borders were also highlighted, given the lack of mechanisms currently to support this in many countries.

Participants also highlighted the issue of data governance and data protection as the various data sets are usually held and managed by different organisations, and data sharing is often underpinned by diverse legal frameworks. This can be a significant impediment to integration in federal systems (as reported by Canada and Pakistan), where subnational entities must legislate privacy agreements with national entities. Where surveillance is funded by development partners, the legal arrangements with local agencies mean the data cannot be used without the partner's permission. It was also important to consider the integration of public and private surveillance systems, especially in countries such as Pakistan and Mozambique, where a substantial proportion of health care is delivered by private providers.

While formal systems or mechanisms for sharing data and intelligence across agencies exist in some countries (e.g., Sweden), in others inter-agency data sharing can be problematic. For countries where there was no formal mechanism for sharing data and intelligence across agencies, interpersonal relationships and networks were vital. Participants described how these relationships and networks facilitated sharing and led to a greater willingness to work together to overcome impediments encountered. Trust was a key facilitator built through a history of collaborative working and having open lines of communication and dialogue. In Canada, participants stated that data sharing between the provinces and territories and the national government could only succeed with trust between the various levels and through well-established networks such as the Canadian Network for Public Health Intelligence (CNPHI). Some of the informal mechanisms for data sharing tended to rely on individuals and interpersonal relationships. As one participant in England noted, it depends on 'enthusiastic individuals', which emphasised the importance of individual personalities rather than institutional mechanisms.

Financing

Participants noted a lack of sustained funding and investment to drive integration. The lack of resourcing was felt more acutely by participants from LMICs. In Uganda and Malawi, surveillance activities received external donor support, but the funding was typically earmarked for specific activities and donor-driven interests, thereby diverting resources away from the national system and leading to fragmentation and duplications across parallel systems. Participants from Pakistan and Mozambique noted their reliance on external support to develop and sustain surveillance systems. In all countries, surveillance systems were dependent on funding from national governments, and therefore, IDS development was contingent on political support. However, as one England participant reflected, there was far less interest in funding surveillance compared to research and development.

Resourcing requirements

Of the different resourcing requirements for IDS, workforce constraints were common, as reported by Pakistan, Uganda, Mozambique and England. IDS is more than just the integration of data sets but requires a skilled workforce able to process, analyse and interpret integrated surveillance data, as well as ensure data quality and understand the strengths and weaknesses of different data sets. In a number of countries, including Mozambique, Sweden and England, participants highlighted the need especially to strengthen

expertise in data visualisation and translation of data for decision-making. Initiatives such as the Field Epidemiology Training Program (FETP) were cited by some participants as a potential source of skilled epidemiologists to support surveillance activities.

Impact of the COVID-19 pandemic on IDS

In most countries, the COVID-19 pandemic revealed gaps in surveillance systems and helped raise to prominence surveillance activities at the national level. It focused political attention on disease surveillance and heightened awareness of the need for good-quality surveillance information and systems. Participants from several countries acknowledged that the pandemic had helped their public health sector acquire equipment and funding, and spurred innovation in electronic surveillance systems. The scale and urgency of the pandemic also helped to emphasise the role of NPHIs and increased public awareness and media attention toward public health surveillance outputs and activities. However, this also increased scrutiny of government and public health action.

The type of data collected through existing surveillance systems during the pandemic was reportedly not at a sufficiently granular level to identify and understand patterns of risk and vulnerability needed to tailor response efforts to certain populations or geographic areas. Some data sets needed to be manually enhanced with additional information, such as location, to be useful for contact tracing. Participants in Sweden and England further commented on the need to be more efficient in the allocation of resources for surveillance. For example, it was noted that during the pandemic, there was an excessive amount of data collected that could not all be analysed due to limited surveillance analytical capacity. The pandemic also highlighted the potential role of harnessing non-traditional sources of surveillance data, such as social media activity, and the need to evaluate their relative utility and reliability moving forwards.

Over the course of the pandemic, there was a heavy reliance on laboratory and diagnostic capacity in all countries. This revealed the need to strengthen these capacities — in terms of physical infrastructure, transport, equipment and supplies, and human resources — at both a national and subnational level to activate the appropriate response efforts rapidly. Finally, participants from Uganda, Pakistan, Malawi, and Mozambique noted that the high level of investment in the COVID-19 response came at the expense of other priority pathogens where surveillance was interrupted.

Discussion

Unsurprisingly, disease surveillance systems around the world are at different stages of integration and development. There is a plurality of surveillance systems, including within countries, that evolved over time to address specific needs. The challenge of integrating these disparate systems, and the costs of doing so,[7] should not be underestimated. This highlights the importance of considering not only the purpose of integrating surveillance systems but also the expected costs, outputs and benefits,[15] particularly in resource-limited settings. Greater integration will come at a greater expense but the incremental benefit gained may reduce. It also raises the question as to whether such benefits can be more efficiently and easily achieved through strengthening existing surveillance systems. The existence of non-integrated but well-functioning surveillance systems in HICs suggests that alternative models of integration that do not entirely require a single platform may indeed be possible.

Across the deep-dive countries, a number of common priorities emerged as key areas for moving forward. These priorities focused on: 1) establishing a common understanding of IDS definition and purpose; 2) optimizing the governance and legal environment for integration; 3) formalizing collaborations between sectors, systems, and key stakeholders; 4) streamlining data processing functions; and 5) investing in a surveillance workforce including continuous training and development. From the four LMIC reports, the concept of IDS and the WHO-defined IDSR strategy were more or less synonymous. For the HICs studied, many were unfamiliar with the IDS/IDSR terminology but understood broadly the concept and need for integration of disease surveillance systems. Governance across systems and agencies, including data protection and privacy concerns, and legislation to support interaction across sectors and agencies were important enablers. Where funding is externally driven, integration has 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.

Our findings also point to the importance of having not just the hardware and processes for surveillance but also a public health workforce with the right skills to manage surveillance and make the best use of surveillance outputs.[7] Furthermore, the findings indicate that the way in which these key individuals are linked and networked is essential, particularly for informal intelligence sharing. When networked together, these professionals form trusted communities of practice that also facilitate learning and problem-solving.[16] However, this also poses challenges to the consistency of information shared and the sustainability of informal sharing mechanisms that are dependent on individuals instead of institutional processes. 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.

What is also apparent from the COVID-19 pandemic is that there is increased interest and effort to integrate different surveillance systems during outbreaks, but there is a risk that momentum is lost once the outbreak has been managed and the perceived threat has passed. This suggests that the current case for more integrated surveillance in many 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.

In terms of public health practice, our study highlights the need for clarification of the purpose of IDS through an explicit guiding definition, especially in terms of what 'integrated' means, what it seeks to achieve, and how integration is delivered in a specific context. This will require consideration of building a surveillance infrastructure that is interconnected and has interoperability at every level and across sectors of the system.[17] Also key to achieving an effective integrated disease surveillance system is the need to strengthen the workforce, through establishing and formalising professional networks, ensuring adequate staffing, and capacity building to provide the infrastructure, tools, skills and expertise needed to operationalize IDS.[7] It is also clear that integration requires considerable resourcing and political backing to ensure that there are sustained funding and adequate levels of investment to drive systems integration. There needs to be clear ownership of the integration agenda, and NPHIs could play a key role as catalysts and system leaders for IDS.

There remain research gaps such as the need for further evidence as to how to best operationalise IDS in reality, bearing in mind the diversity of country contexts and surveillance system maturity, and economic evaluation of surveillance systems.[15] Areas for further research include exploration of how surveillance systems can be most efficiently and effectively strengthened, including identifying which aspects of existing surveillance systems when integrated will optimally increase the efficiency, effectiveness and

utility of data collection, analysis and use. There is a need to facilitate opportunities for research, evaluation and learning to strengthen expertise as well as improve and assure the quality of surveillance, as well as identify new alternative data sources that can be exploited to enhance disease surveillance.

This is the first global situational analysis of IDS in the context of the COVID-19 pandemic, jointly conducted in partnership with different NPHIs in a twinning approach. The use of qualitative methods provides a useful snapshot of the existing realities of IDS in its operational contexts. Some limitations should be noted. One potential issue is generalisability as only seven countries were covered, with no representation from the Western Pacific, Southeast Asia, or South America. However, we were able to ensure enough heterogeneity that allowed for external validity of the results.[18] Whilst efforts were made to standardise data collection, some variation in approach was likely as data collection had to be conducted by separate in-country teams organised by the NPHIs due to logistical constraints. That said, having trusted local NPHI data collection teams was advantageous such as familiarity with local context, culture, norms and language. Finally, it is possible that not all key stakeholder perspectives were captured, such as those of development funders and private organisations, and there is the possibility of response bias among those who did participate.

In conclusion, there is a diversity of disease surveillance systems worldwide, at different stages of maturity and integration. Each system has its own particular challenges, constraints, strengths and opportunities. They have evolved organically, influenced by their local context, as well as legal, financial and policy determinants. If the aim is to sustainably strengthen disease surveillance globally, this requires context-specific strategies to be devised at the national level with the aim to improve surveillance over time, supported with adequate financing and resourcing, including consideration of the workforce and skills required. Stepwise improvements rather than radical resource-intensive change are more likely to be successful. There may be added value too in the sharing of experiences and learning between countries. The WHO IDSR strategy is one possible approach that may help guide the development of surveillance systems to achieve this aim, but the ultimate purpose sought for surveillance must guide integration efforts.

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Ethical approval

An ethics waiver was sought and granted by the institutional ethics review board for Emory University, an IANPHI member, on behalf of IANPHI.

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Competing interests

AL is the co-editor-in-chief of the journal.

Appendix A. Supplementary data

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