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The state of integrated disease surveillance globally: synthesis report of a mixed methods study

Andrew C.K. Lee [a, g, *], Bjorn G. Iversen [b], Sadaf Lynes [c], Jean-Claude Desenclos [d, h], Janine E. Bezuidenhoudt [e], Gerd M. Flodgren [b], Thidar Pyone [f]

[a] The UK Health Security Agency, UK
[b] Norwegian Institute of Public Health, Norway
[c] International Association of National Public Health Institutes, Belgium
[d] the University of Sheffield, Sheffield, UK
[e] National Institute for Communicable Diseases, South Africa
[f] World Health Organization, Geneva, Switzerland
[g] The University of Sheffield, Sheffield, UK
[h] The University of Sheffield, Sheffield, UK

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ABSTRACT

Objectives: Disease surveillance is an essential public health function needed to prevent, detect, monitor and respond to health threats. Integrated disease surveillance (IDS) enhances its utility and has been advocated for decades by the World Health Organization. This study sought to examine the state of IDS implementation worldwide.

Study design: The study used a concurrent mixed methods approach consisting of a systematic scoping review of the literature on IDS, a survey of International Association of National Public Health Institutes (IANPHI) members and qualitative deep dive case studies in seven countries.

Methods: This report collates, analyses and synthesises the findings from the three components. The scoping review consisted of a review of summarised evidence on IDS. Eight reviews and five primary studies were included. The cross-sectional survey was conducted of 110 IANPHI members representing ninety-five countries. Qualitative case studies were conducted in Malawi, Mozambique, Uganda, Pakistan, Canada, Sweden, and England, which involved thirty-four focus group discussions and forty-eight key informant interviews.

Results: In the different countries, IDS is conceptualised differently and there are differing levels of maturity of IDS functions. Although the role of National Public Health Institutes has not been well defined in the IDS, they play a significant role in IDS in many countries. Fragmentation between sectors and resourcing (human and financial) issues were common. Good governance measures such as appropriate legislative and regulatory frameworks and roles and responsibilities for IDS were often unclear. The COVID-19 pandemic has strengthened some surveillance systems, often through leveraging existing respiratory surveillance systems. In some instances, improvements were seen only for COVID-19 related data but these changes were not sustained. Evaluation of IDS was also reported to be weak.

Conclusions: Integration should be driven by a clear purpose and contextualised. Political commitment, clear governance, and resourcing are needed. Technology and the establishment of technical communities of practice may help. However, the complexity and cost of integration should not be underestimated, and further economic and impact evaluations of IDS are needed.

* Corresponding author. Tel.: +44 7554725671.
E-mail addresses: andrew.lee@ukhsa.gov.uk, andrew.lee@shef.ac.uk (A.C.K. Lee).

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Introduction

Disease surveillance is one of the twelve essential public health functions advocated by the World Health Organization (WHO)[1] and needed to prevent, detect, monitor and inform the response to health threats. This public health function is often led by a country's Ministry of Health (MOH) and usually coordinated and managed by a National Public Health Institute (NPHI) or equivalent department in the MOH. The utility of surveillance outputs can be enhanced through greater functional integration across the different surveillance systems and when linked into public health policy decision making, response and planning. Moreover, multisectoral collaboration and integration of surveillance are particularly vital for threats that have human, animal and environmental health overlaps.[2]

However, the COVID-19 pandemic exposed weaknesses in disease surveillance systems globally highlighting potentially catastrophic consequences arising from failure to adequately prepare and respond to such major threats.[3] This has prompted a renewed focus on the need for pandemic preparedness and for funding mechanisms to catalyse it. In September 2022, the Financial Intermediary Fund (FIF) for pandemic prevention, preparedness and response was set up to provide a dedicated stream of additional, long-term financing to strengthen Pandemic Preparedness and Response capabilities in low- and middle-income countries (LMICs).[4] The FIF was later renamed as the Pandemic Fund and officially launched on November 13, 2022 at the G20 meeting in Bali, Indonesia.[5] The WHO also established a new Hub for Pandemic and Epidemic Intelligence in Berlin in September 2021[6] and announced plans for a new 'Global Pandemic Radar', an advanced international pathogen surveillance network, with the aim to identify and track new COVID variants and emerging diseases.[7] These initiatives provide a window of opportunity for strengthening disease surveillance in countries worldwide.

One approach advocated by the WHO for strengthening disease surveillance in countries is the concept of integrated disease surveillance (IDS),[8] later renamed as Integrated Disease Surveillance and Response (IDSR). The WHO IDS concept sought to improve the usability of surveillance and laboratory data to help enhance detection and response to the leading and emerging health threats. However, the extent of the implementation of IDS worldwide was not known. Neither was there a good understanding of the enablers or barriers to implementation nor of the evidence of effectiveness to justify integration. Consequently, a multicomponent study was undertaken by the International Association of National Public Health Institute (IANPHI) to document the current state of knowledge, understanding and implementation of IDS worldwide, as well as to identify key barriers, enablers and opportunities for innovative developments, considering some of the lessons learned from the COVID-19 pandemic. It was intended that the study findings would help inform areas for investment to develop and strengthen surveillance systems further, and better understand how greater integration may improve the effectiveness and efficiency of national surveillance systems and response to health threats. Moreover, the insights gained could help identify key priority actions to enhance collaboration across sectors for data integration and better articulate the role of NPHIs and key actors involved in surveillance.

Methods

The study used a concurrent mixed methods approach[9] consisting of a systematic scoping review of the literature on IDS, a survey of IANPHIs members and qualitative case studies in three High-income Countries (HIC) (Canada, England, and Sweden) and four LMIC (Malawi, Mozambique, Pakistan, and Uganda) (Table 1).

The scoping review[10] was a review of reviews that included summarised evidence (e.g. scoping reviews, rapid reviews, systematic reviews, literature reviews, narrative reviews and meta-analysis) from Medline, Embase, Epistemonikos and web portals of three key organisations. The review included papers published in English between 1998 and 2022.

The cross-sectional survey[11] was conducted online using SelectSurvey v5.0 of 110 IANPHI members representing ninety-five countries (Table 2). Respondents were individuals in a senior position from the member country's NPHI or MOH, who was likely to have access to the wide range of information related to surveillance and IDS that was needed to complete the survey. Respondents were provided with Nsubuga et al.'s definition of IDS (IDS can be described as a combination of active and passive systems using a single infrastructure that gathers information about multiple diseases or behaviours of interest to ensure robust early warning and a prompt public health response)[12] and asked to self-report whether their country had a fully developed, partially developed or no IDS system in place.

Qualitative 'deep dive' case studies[13] were conducted in seven countries: Malawi, Mozambique, Uganda, Pakistan, Canada, Sweden and England. Thirty-four focus group discussions and forty-eight key informant interviews were undertaken with total 271

Table 1
The three study components of the IDS project.

Components	Objectives	Methods	Sources of information
Systematic Scoping Review	To document the current state of knowledge, conceptualisation, and implementation of IDS	Systematic review of the literature	Medline, Embase, Epistemonikos, and web portals of three key organisations (WHO, USCDC & Médecins Sans Frontières)
Multicountry survey of IANPHI's membership	To understand how IDS is conceptualised by NPHIs and explore existing surveillance systems and maturity models in terms of linkages between surveillance systems, roles, opportunities availed and challenges to integration across systems, sectors, infrastructure, and professionals.	Online survey with IANPHI members	65 NPHIs from IANPHI's membership responded
Country 'deep dive' case studies	To explore the current barriers, challenges, and enablers of an 'IDS' system; what is meant by IDS according to country context; how IDS is delivered including enablers; and opportunities and innovations for implementation.	Multisectoral focus group discussions and key informant interviews	Qualitative studies conducted in seven countries (three HIC and four LMIC)

IDS: Integrated disease surveillance; HIC: High Income Country; LMIC: Lower Middle Income Country; NPHI: National Public health Institute; US CDC: United States Centres for Disease Control & Prevention; WHO: World Health Organization.

Table 2
Survey responses as a proportion of IANPHI member institutions by World Bank income group and WHO region.

	Members of IANPHI	Invited to the survey	Responded to the survey	% Response
World Bank income group	High income	32	23	72%
	Upper middle	25	15	60%
	Lower middle	34	15	44%
	Low income	19	11	58%
Total according to WB's income group		**110**	**64**	**58%**
WHO Regions	Africa	32	17	53%
	America	15	14	93%
	Eastern Mediterranean	12	5	42%
	Europe	37	22	59%
	Southeast Asia	7	2	29%
	Western Pacific	7	4	57%
Total according to WHO Regions		**110**	**64**	**58%**

participants (98 national levels, 87 provincial or state or regional level and 86 district level and below). Purposive sampling was used 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, to obtain a broad range of perspectives.

This paper synthesises the results from the three components and presents the analysis, identified themes, reflections and recommendations emerging from them. Full details of the separate components, including methodology and findings, are published in separate reports elsewhere.[10,11,14,15]

A bespoke conceptual framework (Fig. 1) was developed based on the WHO IDSR framework[16] and including key principles proposed by Morgan et al. (2021).[3] The conceptual framework identifies five key thematic domains: Governance, System/structure, Financing, Core functions of surveillance, and Resourcing requirements. The framework informed the development of the methodology for the three components, as well as guided the categorisation of findings and subsequent analyses.

Results

The results are presented starting with summaries of the key findings from scoping review, multicountry survey and deep dives, followed by consolidated findings according to the five domains of the conceptual framework (governance, systems and structure, financing, core functions, resourcing requirements) and the impact of the COVID-19 pandemic on IDS.

Key findings from the scoping review

Eight reviews and five primary studies, published between 2009 and 2021, were included. The included evidence for IDS conceptualisation and operationalisation was fragmented, incomplete, and of low quality. There was no common IDS definition and there were no articles reporting on the effect of IDS systems implementation on disease control outcomes. Findings support the conceptual framework used. Reported pre-requisites for an effective IDS system included the need for better quality data, adequate staffing with the right skills, improved laboratory capacity, digitisation, standardised protocols, guidance and bi-directional feedback, as well as consistent processes and interconnectivity. Other reported pre-requisites were improved governance, government commitment to operationalise IDS, good leadership, increased staff training and the adoption of electronic/mobile reporting. Included articles described the provision of core functions and resourcing requirements (e.g. human resources, laboratory capacity, and digitisation) as generally inadequate, especially at the health facility and regional levels. However, whilst electronic solutions can

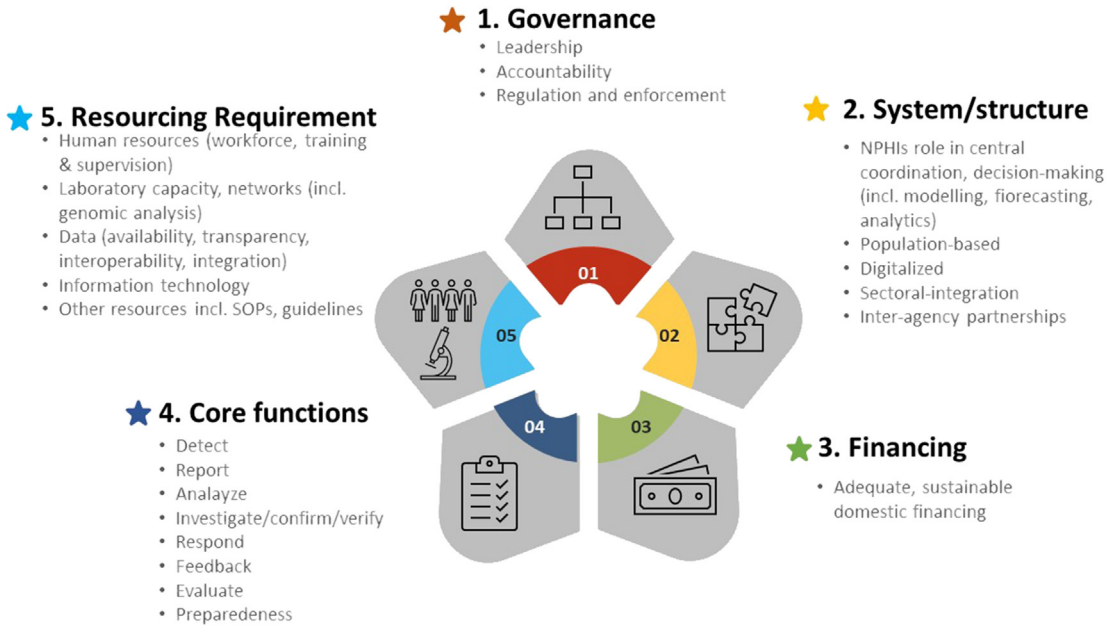

Fig. 1. Conceptual framework of the study.

enhance surveillance activities, dysfunctional technology can be a barrier. Sources of financing of IDS were not outlined in any of the included articles. When mentioned, financing was described as non-sustainable and a major challenge. Laws and regulations that could facilitate data sharing were not discussed in any of the included articles. Examples of enablers identified included active data sharing, close cooperation between agencies, clear reporting channels and integration of disease control programs.

Key findings from the survey

Of the 110 IANPHI member institutions surveyed, sixty-five participated in the survey. Respondents were asked to assess the level of maturity and implementation of IDS in their country to which most reported having a partially developed IDS system. One in four reported having a developed IDS system while 20% reported having no IDS system in place. Surveillance systems were often led by the MOH (45%), but NPHIs in many countries also had a key role in surveillance. The survey found interpretations of 'IDS' differed from country to country. Good governance was needed, such as adequate legislative and regulatory frameworks, appropriate control, monitoring and evaluation, as well as data management and regulation to ensure data integrity, confidentiality and interoperability. Examples of good practice reported included the enabling role of technology such as greater automation, electronic reporting systems, algorithms and data platforms.

However, integration challenges existed at the interfaces between different organisations, levels and sectors, including the private and pharmaceutical sectors, as well as non-human health and non-communicable disease sectors. Adequate resourcing (including financing) was also a common need, but external donor financing could hinder integration by creating siloed disease-specific surveillance systems. Other challenges identified pertained to constraints in supporting technology and workforce capacity and skills required for robust data analysis. Whilst the COVID-19 pandemic has strengthened most, but not all surveillance systems, often through leveraging existing respiratory surveillance systems. For some, the improvements were seen only for COVID-19-related data, and most of the system changes were not sustained.

Key findings from the deep dives

In the four LMICs studied, most of the core IDS elements were in place, but further improvement was needed in areas such as governance, human resources, funding, data quality, and digitisation. There were challenges with integrating data from health facilities and laboratories, as well as between human and animal health sectors. There were also issues with data quality, lack of laboratory confirmation of cases, and lack of good civil registration and vital statistics. There was a need to improve laboratory and surveillance data collection, validation, analysis, interpretation, and reporting at all levels. Digitisation may help but is hampered by the slow introduction of electronic medical records. Other barriers included deficient supporting legal frameworks, lack of clear purpose, fragmented ownership of surveillance, varying political support for IDS, under-resourcing especially with regards to skilled staff. There is a need to develop local knowledge, and high trust networks and relationships between professionals, agencies and sectors, at all levels of the system.

For the three HICs studied, there was no consensus as to what integration means and even unfamiliarity with the IDS concept. Concerns included the difficulty and cost of developing an IDS system that may prove 'unwieldy.' None of the HICs had an IDS system, but all had examples of highly developed, well-functioning surveillance systems that were widely used. Again, this highlighted the importance of clarity of purpose of integration. Where integration was lacking, intelligence sharing and problem solving occurred through high trust professional networks. Areas for improvement included greater automation, clarification of data protection and confidentiality concerns and better standardisation of processes. The quantity of data tended to exceed analytical capacity hence prioritisation of surveillance activity was required. However, surveillance needs differ between different stakeholders and national and local levels. The extent of multisectoral integration also varied and public involvement tended to be limited. Whilst NPHIs tended to have a major part in disease surveillance and disease control, their mandates, independence from government, and authority, also varied considerably from country to country.

Cross-cutting themes

There were seven major cross cutting themes and emerging recommendations identified based on the key findings from the three components, as follows:

- IDS: What it means in different country settings

Integration is more than just the integration of data and IT infrastructure or the summation of data. Integration must be conceptualised across a spectrum of systems, capacities and activities. Enhancements to the core principles from the Morgan et al. paper and additional core principles are needed such as governance, legislation, human resources, effective system attributes as well as having a multisectoral approach. Data systems should include One Health data, data from the public and private sectors, and include both laboratory and clinical information.

- The role of NPHIs and Public health entities/departments

The role of NPHIs in IDS is often not clearly defined. In many countries where there are NPHIs, the NPHIs play a major part, particularly for the core functions of surveillance. NPHIs in both LMIC and HIC settings play a role in IDS, the extent of which is dependent on the scope of their mandate and powers.

- Levels of maturity of IDS functions across countries

Countries are at differing levels of IDS system development. Integration most commonly occurs in the human health sector, but multiple barriers exist that affect data availability, interoperability, coverage, capacity and coordination. Digitisation, including the potential use of unique health identifiers and electronic records/documentation, may help. Other enablers for IDS development include supporting IT infrastructure, supportive legislation, sustainable funding, together with workforce training and capacity building. Integration of vertical and externally donor-funded programs were also less common.

- Roles and responsibilities in fragmented and integrated systems

The governance, roles and responsibilities of the IDS systems were typically not described nor discussed in the literature which focused almost entirely on the core functions of surveillance and the resourcing requirements of IDS systems. Technology, professional and laboratory networks, as well as supportive legislation, may help overcome some of these issues. Improved governance and clear organisational mandates are also needed at all levels of the IDS system.

◆ Multisectoral integration

Fragmentation and the lack of integration between sectors was evident, particularly regarding the One Health strategy. Vertical disease-specific systems are particularly problematic in LMICs in terms of data linkages and accessibility, and partly due to donor requirements. Integration also tended to be particularly weak for the private and pharmaceutical sectors, and the non-health sectors. Active collaboration between health and non-health sectors is needed to ensure that data collected in different sectors can be used and integrated for public health surveillance, as well as promote data collection standards and protocols across sectors.

◆ Core Functions: *Detect, Report, Analyse, Investigate/confirm/verify, Respond, Feedback, Evaluate and Preparedness*

Results from the literature suggest overall inadequate core surveillance functions in many countries. The self-reported performance of the core functions tended to be weaker in LICs, particularly for the '*report*,' '*evaluate*' and '*feedback*' elements. Weak '*evaluation*' function was common to both LICs and HICs. IDS systems need to be systematically assessed, and they require enhanced feedback mechanisms at all levels to not only optimise day-to-day functioning, but also to identify gaps and weaknesses in the core functions for improvement, with consideration of the 'human factor' in surveillance functions.

◆ Resourcing requirements

The different systems organised by different authorities make coordination and cooperation difficult. However, making wide scale changes to existing surveillance systems would require significant resourcing and funding that are contingent on adequate political support. Political support would also be needed to ensure there is clarity of governance structures and enabling legal and regulatory framework. There is also a major need to invest as part of an active and sustained national policy in workforce capacity, development and retention. Laboratory and IT infrastructure are essential, and need to be maintained, integrated, and developed, across various levels and sectors. LMICs are heavily reliant on external funding for their systems, but this may exacerbate fragmentation of surveillance systems. Consequently, donors/funding agencies are key actors in these settings and have a critical role to play in fostering and maintaining IDS systems. It is also important to consider the ethical dimension and privacy protection of surveillance systems.

◆ Impact of the COVID-19 pandemic on surveillance

Country responses to the pandemic have shown that there is potential to improve surveillance effectiveness through leveraging existing surveillance systems and cross-sector collaboration. The pandemic legacy of good practice and innovative COVID-19 surveillance initiatives could be used to improve current systems. Sustaining these developments will require appropriate funding, resources, workforce development and infrastructure, and alignment to priority needs. There is an urgent need to identify sustainable levels of investment needed to strengthen existing surveillance systems, whilst maximising the efficient and effective use of limited resources.

Discussion

The consolidated results of this mixed methods study found a lack of a common understanding of IDS as IDS was interpreted differently across countries. The study observed that integration is more than just the integration of data and IT infrastructure or the summation of data. Integration has to be conceptualised across a spectrum of systems, capacities and activities. The study findings support the domains in our conceptual framework, emphasising the importance of system-level determinants such as governance, systems and structure, political support, financing and workforce for effective IDS. The need for good governance and leadership at both national and sub-national levels was also corroborated by the findings of the scoping review in other studies.[17–19]

The study highlights the importance of functioning surveillance systems and infrastructure that enable the collection, validation, analysis, interpretation and reporting at all levels of the system. George et al. (2020)[20] previously highlighted that for IDS systems to be effective it needs interconnectivity, interoperability, semantic consistency, and convergent integration across sectors. Flexible systems that enable bi-directional information sharing are required for IDS, but issues with data governance and data protection as well as interoperability within and across ministries are often encountered.[21] Leveraging digital technology could improve the timeliness and quality of data with reduced costs,[22] but this study observed bottlenecks due to incompatibility and limited interoperability among different systems. Technological disparities between countries exist with some countries still reliant on paper-based reporting especially at the health facility level.[20] Data systems should adopt a One Health approach, incorporating data from the public and private sectors, and include both laboratory and clinical information.

This study also found issues with the financing of IDS. Domestic financing for IDS was often not sustainable. International financing tended to be less reliable and often earmarked for disease-specific programmes that may undermine national efforts to integrate systems. These issues with financing are not new and have previously been identified.[19,20,22–24] Similarly, the workforce challenges identified by both the survey and deep dives echo other studies in the scoping review that highlighted the lack of skilled designated surveillance personnel, inadequate training, and high staff turnover at the peripheries as major challenges to a functional IDS system.[25,26] Limited and irregular supervision, especially at the district level, was another reported problem.[19,22,24,26] Training was also typically limited to regional and national levels only.

The COVID-19 pandemic has shown how weak surveillance limits early detection and rapid response to health threats.[3] For future epidemic and pandemic threats, an integrated surveillance system using a broad-based, multisource horizontal platform able to detect different pathogens is needed. The system should capture not only disease incidence and location, but also useful contextual information such as sociodemographic information, utilisation of health services and the availability of health resources, to help inform the right policy and response decisions. There is also a need to explore the potential role of harnessing non-traditional sources of surveillance data such as social media activity and to evaluate their relative utility and reliability moving forwards. Importantly, surveillance systems need to be able to be scaled up quickly to respond to a new threat. The concept of integrated surveillance also is evolving, with the WHO currently promoting the concept of 'collaborative surveillance' in part informed by the output of this study. This is described as 'the systematic strengthening of capacity and collaboration among diverse stakeholders, both within and beyond the health sector, with the ultimate goal of enhancing public health intelligence and improving evidence for decision making'.[27]

The complexity and costs of integrating surveillance systems should not be underestimated, especially in terms of the infrastructural requirements such as information governance, the balance between public welfare and individual right authorship of the

data and flexibility of the system. There is no one-size-fits-all model for surveillance and its integration, and what is implemented has to take into consideration each country's unique circumstances, context, needs, priorities, resources, constraints and legal frameworks. IDS implementation, therefore, needs substantial political commitment to ensure it receives the necessary backing and resourcing, as well as supporting legislation and governance. There is also a need for donors, ministries of health and NPHIs, to better coordinate their efforts and resources. IDS implementation needs to be guided by a clearly defined purpose linked to achieving beneficial health outcomes in order to justify the investment needed. It is a multisectoral endeavour requiring effective collaboration between the different stakeholders engaged in disease surveillance, preparedness and response. This requires clearly defined ownership, roles and responsibilities, as well as a sustained skilled workforce, working in high-trust professional networks. These communities of practice are a key enabler of IDS and require input to set up, nurture and sustain, a role that NPHIs are well placed to perform. Such communities of practice allow for shared learning and problem solving, knowledge exchange and dissemination of best practice.

Notably, there were two other separate but contemporaneous IDS studies with complementary findings. One similar study led by the Robert Koch Institute (RKI) consisted of a scoping review and qualitative substudy with case studies conducted in Namibia, Côte D'Ivoire, Madagascar and Saudi Arabia, with a strong focus on workforce and laboratory development.[28] The RKI study identified the need for better integration between epidemiology and laboratory surveillance, better data quality and management systems, increased laboratory capacity and organisation, better data sharing, as well as improved the quantity, quality and coordination of workforce development and training. Another study led by Resolve to Save Lives examined how surveillance operates in several countries such as Liberia, and Nigeria. They identified similar findings such as the lack of organisational maturity, unstable funding sources, unclear governance, lack of staff training, software and data management challenges and lack of big-picture thinking.[29] Their key recommendation was the need to focus on the IDS architecture for systems, data, software, standards, guidelines and tools.[30]

Limitations

The various components of this study do have some limitations that are reported elsewhere. In brief, much of the existing published literature on IDS is judged to be of poor quality and mostly conducted in the African region. Likewise, the deep dives were focused on just seven countries, and the multicountry survey lacked sufficient representation from some regions (Southeast Asia, Eastern Mediterranean). Consequently, the findings may not be representative or generalisable elsewhere. Moreover, study participants were primarily recruited from IANPHI member countries; hence, the experience of non-member countries may not be adequately captured. The study also sought a high-level overview of the state of IDS implementation worldwide, and therefore, does not have detailed granularity on integration at the subnational level or for specific surveillance programmes. The study provides an overview on the global status and understanding of the concept of integration of surveillance. Although discussed in the qualitative country deep-dives, the various components of IDS like indicator-based and event-based surveillance, risk assessments and responding to alert signals were to a lesser degree specified in the reporting. There is considerable diversity of experience of integration worldwide, so what is reported here reflects just a few of the common themes within a limited number of contexts. Finally, the richness of the study findings is more fully described in separate publications of the three components of this study.

Future research

There are, however, some knowledge gaps that this study did not address where future research is needed. First, there are no universal, validated metrics by which to measure the extent and level of maturity of integration of surveillance systems. It is also currently unclear which aspects of existing surveillance systems when integrated will enhance the utility of surveillance data for improved response in different settings. Further exploration is, therefore, needed to identify ways to efficiently and effectively strengthen surveillance systems. Finally, there is a paucity of economic evaluations and impact evaluations of IDS on disease control, information that is essential for justifying the investments in IDS. Intuitively, integration disease surveillance makes sense but there is no robust evidence that it delivers the expected benefits in practice, particularly because it has not been sufficiently assessed.

Conclusions

Based on the findings of this study, three key recommendations emerge for policy and public health practice. First, there is a need to properly define IDS, as well as articulate fully the purpose, scope and organisation of the IDS systems to be operationalised at the national and subnational levels. Second, a strategic approach to planning for the implementation of IDS is needed. Countries, with the support of partners, should review and evaluate their existing surveillance systems and determine how IDS can be best implemented assuming this is deemed as the best approach for the specific country context. Finally, before implementing IDS, countries need to consider whether multiple collaborative structures that are interconnected and communicate well might be a better choice than the use of a single infrastructure for disease surveillance due to the complexity of surveillance systems and costs involved. Ultimately, the value of any surveillance system is its contribution to better disease response and control. The integration of disease surveillance may help achieve this, but integration is not the ultimate endpoint. A collaborative approach, such as the integrated multisectoral One Health approach,[31] and collaborative surveillance concept for strengthening health emergency preparedness, response and resilience[32] advocated by the WHO, may provide a better solution to the fragmentation of surveillance that exists in many countries.

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Competing interests

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

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