From the evolution of Information Systems for Health to the Digital Transformation of the Health Sector

IS4H CONFERENCE REPORT



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From the Evolution of Information Systems for Health to the Digital Transformation of the Health Sector

IS4H Conference Report

Washington, D.C., 2021



From the Evolution of Information Systems for Health to the Digital Transformation of the Health Sector. IS4H Conference Report

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EIH/IS/2021

DIGITAL TRANSFORMATION OF THE HEALTH SECTOR IN THE REGION OF THE AMERICAS

"We need to take a fresh look at public health, one that is much more holistic and inclusive, that considers new critical factors for the success of interventions, such as connectivity, bandwidth, interoperability, artificial intelligence, among others. This renewed approach must also consider inequities in the digital era to ensure that the digital divide does not widen the gaps in health inequities."

Dr. Carissa F. Etienne, PAHO/WHO Director



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DIGITAL TRANSFORMATION IN PUBLIC HEALTH

"The COVID-19 pandemic has exposed the need for health systems to be "more resilient, interdisciplinary, intersectoral and interconnected than ever...It may seem obvious, but to achieve the goal of leaving no one behind, first we need to know that this person does exist; we need to know where he or she is, and we need to know what their social and health situation is. It is also imperative to consistently know the state of our health systems and their ability to respond to the particular needs of individuals, their communities and families. And the only way to know this is if we have information systems capable of capturing and processing critical and disaggregated data and making it available to the entire health system without exceptions."

Dr. Carissa F. Etienne, PAHO/WHO Director

1. Overview

This Information Systems for Health (IS4H) Conference, From the Evolution of Information Systems for Health to the Digital Transformation of the Health Sector, was organized by the Department of Evidence and Intelligence for Action in Health of the Pan American Health Organization (PAHO). This event aimed to create a dialogue of reflection with the countries of the Region of the Americas on their experiences regarding their information systems and digital health during the last four years, and in particular during the COVID-19 pandemic.

The event attracted approximately 150 participants from all countries and territories of the Americas, regional and international development partners, PAHO/WHO Collaborating Centers, and academic institutions (see Figure 1). Over three virtual sessions, they reflected on the need for timely, accurate, quality and disaggregated data, critical information and knowledge on health to inform decision- and policymaking, program interventions, monitoring and evaluation in the context of countries' progress to universal access to health and universal health coverage, ongoing national digital transformation initiatives, and the 2030 Sustainable Development Goals.

Discussions at the preparatory sessions (see Annex 1): were organized taking into consideration

the results of the maturity assessment of the 49 countries and territories of the Americas, and were focused on the four strategic goals of the IS4H Plan of Action: (i) management and governance; (ii) data management and information technologies; (iii) information and knowledge-sharing; and (iv) innovation (see Annex 2).

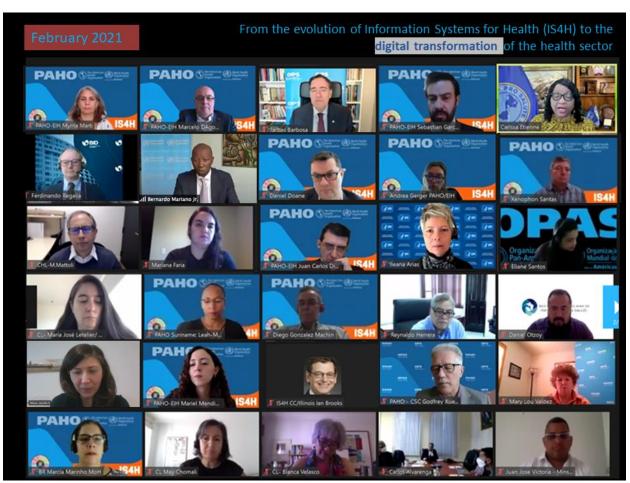
Cognizant of the existence of global and regional political frameworks, and all the existing experience and high-level commitments, the participants recognized the importance or working together with a common goal and under the eight principles for the digital transformation of the health sector presented by PAHO (see Annex 3): (i) achieve universal connectivity in the health sector by 2030; (ii) co-create digital public health goods for a more equitable world; (iii) accelerate progress toward inclusive digital health, with emphasis on the most vulnerable populations; (iv) implement open, sustainable,

interoperable digital information and health systems; (v) mainstream human rights across all areas of digital transformation in health; (vi) participate in global cooperation on artificial intelligence and any emerging technology; (vii) establish mechanisms for the confidentiality and security of information in the digital public health setting; and (viii) design a renewed public health architecture for the age of digital interdependence.

Building on existing actions, taking into consideration this after-action review of four years of IS4H implementation, and considering the regional need to accelerate the digital transformation of the health sector and strengthen IS4H across the Americas, PAHO launched a call to action to ensure that "leave no one behind" becomes a reality in the age of digital interdependence.

This report summarizes the discussions, agreements, main conclusions, and the call to action to position the health sector in the vanguard of digital transformation in public health in the Region of the Americas.

Figure 1. IS4H Conference, Opening Remarks



DIGITAL TRANSFORMATION IN PUBLIC HEALTH

"Digital transformation is a reality that has no turning back, and we are convinced that the benefits of information and communications technologies must become a right of all."

Sebastian Garcia Saiso, Director, Department of Evidence and Intelligence for Action in Health, PAHO/WHO

2. Call to Action

At the very moment when most countries in the world, just as international cooperation organizations, were advancing in the processes of digital governmental transformation, WHO declared the novel coronavirus disease (COVID-19) a pandemic. This pandemic has tested not only health systems, but how all government, academic and private sector actors should work together with a common goal, fighting against the pandemic and for the population's health and well-being. In such a context and in the search for mechanisms to preserve the way of life, there was a process of acceleration in the adoption, as effectively as possible and in the face of a situation of great uncertainty, of information systems, communications technologies, and digital health solutions that have proved crucial to maintaining and strengthening activities across all sectors.

However, Member States agree that there is still a long way to go as digital transformation, which

undoubtedly brings countless benefits, has demonstrated new forms of social exclusion that could amplify existing social, cultural, and economic inequalities in populations without, or with limited, connectivity and bandwidth, as well as digitally distant population groups.

The digitization of health services implies important cultural changes for both health professionals and the general population. Although there are multiple examples of how digital health has positive effects on the effectiveness of health systems, there is still a need for holistic analyses involving not only health authorities, but other critical "nontraditional" partners for health, such as telecommunications, the information technology industry, and big data.

Ensuring everyone's inclusion in digital health is critical, particularly considering the most vulnerable, as to date 3.6 billion people worldwide lack Internet access. This creates an additional challenge in capturing data that could reflect the social and health conditions of many in such circumstances, and that are key for adequate decision-making in health. However, access to digital solutions today is limited by cost, copyright, and intellectual property issues, as well as barriers related to language barriers, age, gender, disability and the lack of digital knowledge, among others.

In mid-2020, the United Nations presented eight areas of collaboration based on recommendations from a high-level panel to make technical cooperation operational in the age of digital interdependence.

Based on the discussions at the two preparatory meetings, and on the basis of all the experience accumulated over the last four years under the IS4H initiative, PAHO has embraced and adapted those **eight principles** to reflect the imperatives of the Digital Transformation of the Health Sector and that now constitute the basis of this call to action (see Figure 2 and Box 1).

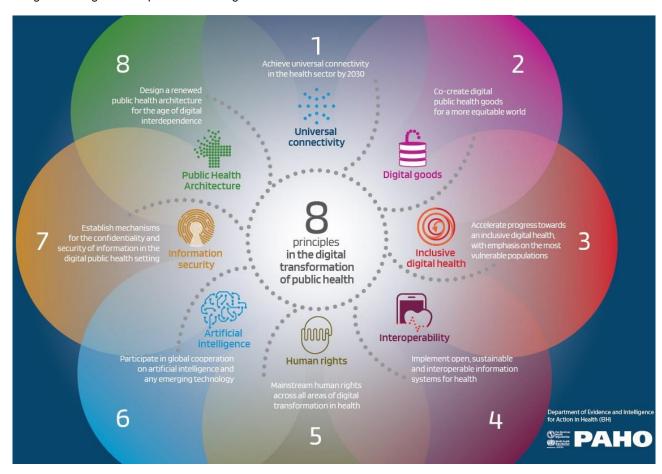


Figure 2. Eight Principles for the Digital Transformation of the Health Sector

- 1. **Universal connectivity.** It is imperative to achieve universal connectivity in the health sector by 2030, addressing the needs and challenges of people, communities, and service providers, and the benefits that will accrue to governments by positioning connectivity and bandwidth as a high priority for public health interventions.
- 2. **Digital goods.** There is a need to co-create digital public health goods for a more equitable world with appropriate architecture and licensing to scale them regionally and globally in different populations and contexts, with the capacity for local adaptation.

3. **Inclusive digital health.** Inclusive digital health should be a "must," and it is necessary to accelerate progress toward inclusive digital health, with emphasis on the

most vulnerable populations; reaching not only populations in conditions of greater social, economic, geographical, or cultural vulnerability but also people and population groups that are not digitally literate.

- 4. **Interoperability.** There is a need to stop seeing "interoperability" as an isolated IT-related term. It is a key concept for having timely open access to properly disaggregated data and the integration of national and local systems.
- 5. **Human rights.** Mainstreaming human rights across all areas of digital transformation in health is one of the most important critical factors for success. Guaranteeing the protection of human rights in digital health requires immediate in-depth action to review legal and regulatory instruments directly or indirectly related to the health sector.
- 6. **Artificial intelligence.** Participation in global cooperation on artificial intelligence and any emerging technology should be part of public health policies. The principle of global cooperative support in artificial intelligence and any emerging technology means including the individual and social dimensions in a globalized interconnected reality that is now part of the human condition.
- 7. **Information security.** It is also imperative to protect sensitive health information, and therefore it is necessary to collaborate and co-create mechanisms for ensuring the confidentiality and security of personal information in the digital public health setting, while simultaneously promoting access and transparency in information and knowledge.
- 8. **Public health architecture.** Public health architecture in the age of digital interdependence should be designed within the framework of a digital governance agenda. This architecture should be cross-cutting, permitting

"Since 2016 and to date, we have made significant progress and we can attest to the level of maturity of information systems of the entire continent.

This has enabled us to have specific road maps and designs for the development and strengthening of information systems based on available evidence and in keeping with a shared framework that enables us to concentrate efforts on local priorities.

This provides us with the necessary confidence to take another essential step together with you toward the positioning of public health in what the Secretary-General of the United Nations has called "The Age of Digital Interdependence."

Jarbas Barbosa da Silva Jr. PAHO Assistant Director

proper coordination of the different areas of governance and achieving optimization of strategic planning and management of the resources allocated to it.

Box 1. The Call

In this way, and considering that digital transformation is a reality that has no turning back, and convinced that the benefits of information and communications technologies must no longer be the power of a few but become a right of all, the Pan American Health Organization invites all Member States and territories, and all institutions and workers in the health sector to engage in these **eight principles** and:

"Having access to data, information, and knowledge, at the appropriate time and in the appropriate format, can be one of the greatest achievements of a digitally transformed public health."

Marcelo D'Agostino, IS4H Coordinator, Department of Evidence and Intelligence for Action in Health, PAHO/WHO **Work together** to have digital transformation driving us to the 2030 Agenda for Sustainable Development

Coordinate actions related to technical considerations and legal frameworks to "leave no one behind"

Motivate global collaboration to guarantee access to the necessary knowledge and information, at the appropriate time and in the appropriate format

Incorporate digital literacy as a public policy from early education

Strengthen foundational aspects and governance mechanisms to make investments and actions focused on IS4H cost-effective, informed, and sustainable

Ensure that all actions related to the digital transformation of the health sector consider at their center the principles and foundations of human rights

3. After-action Review of IS4H Strategic Areas

3.1 Data Management and Information Technologies

This field refers to technology tools and regulatory instruments, standards for electronic health records, the identification and classification of information products, technology infrastructure, and the definition, classification, and integration of health data sources comprised of structured and unstructured data (see Table 1).

Table 1. Data Management and Information Technologies

| Discussion topic | Challenges | Opportunities | Good practices |
|---|---|---|--|
| Management of data | Focus on data not information and communication technologies Real-time data available Analysis of excess mortality Better data management systems and data | Use of unknown or unavailable data Automated selection of causes of death Data science for new knowledge | New data visualization techniques Digital certificate Strategy for quality data and related content classification |
| Use of information and communication technologies | quality Integrative data and standards Supplier and stock management Focus on stewardship and not development | Narrowing technological gaps Adoption of digital development principles Enabling public use of devices for information exchange | Public health clouds National interoperability platforms Digital strategies based on quality analysis Patient portals |
| Regulatory instruments | Open data Standardized procedures International standards tailored to local realities | Development of terminological standards for the registration of causes of death Comprehensive terminology services | Country-level implementation of international standards |

3.2 Management and Governance

This field refers to institutional strengthening for process management, decision-making, and policy-making (see Table 2), based on the different components of an information system for health, with emphasis on: leadership; use of information technology; data production, management, and processing; infrastructure for Internet access; standards and regulations for the development or introduction of software applications and databases; enhanced capacity-building; and review and updating of legislation.

Table 2. Management and Governance

| Discussion topic | Challenges | Opportunities | Good practices |
|-----------------------|--|--|---|
| Mechanisms | Lack of formal governance structures | Formal agreements for the exchange of data and information | Multidisciplinary and intergovernmental governance structures |
| Regulatory frameworks | Interministerial collaboration Lack of modern and appropriate legislation | Health sector involved in the development of legislation in digital health Regulatory frameworks that support the use, management, and exchange of data and information through electronic media, and address the aspects of dissemination, access, privacy, ethics, interoperability, and domain or property | New flexible laws to introduce innovations in digital health Regulatory frameworks that allow secure and ethical implementation of patient portals |
| Public policy | Integrators to eliminate work in silos The move from paper to digital | National agendas including indicators of the IS4H Plan of Action | Digital agendas integrated into the country's digital or innovation agendas |

3.3 Information and Knowledge-sharing

This field refers to active participation by the scientific and academic community, civil society, and information producers and users in the real-time collection or capture of data and information, and facilitation of access to accurate information at the right time and in the right format (see Table 3).

Table 3. Information and Knowledge-sharing

| Discussion topic | Challenges | Opportunities | Good practices |
|--|---|---|--|
| Academic and research institutions In particular, about the level of engagement of the academia in policyand decision-making | Funding for research available for academic institutions Having a governance mechanism or machinery that integrates both academic and government sectors | Academic institutions or professional associations participating in national committees to support implementation of information systems for health Participation in communities of practices to create information services or resources, ensuring that populations in conditions of vulnerability are taken into consideration | Use of methodologies to document lessons learned, experiences, and good practices, and to promote the sharing of knowledge about the implementation of information systems |
| Strategic communications In particular, about infodemic management | Lack of visibility mechanisms for both local and international science | The pandemic has made people more interested in science, a chance that must be used to make science visible and for citizens to participate in research Improving the connection with the mass media to promote ICT for the common good and combat false information | Implementation of a regional program to combat the infodemic Implementation of tools based on artificial intelligence to understand questions in natural language |

3.4 Innovation

This field refers to the introduction of innovative methodological models and technological applications related to the rapid growth of the Internet, the evolution of information technology, and big data, including the health sector's participation in e-government and open government initiatives (see Table 4). It also includes the implementation of a digital literacy strategy to develop a pool of trained human resources to function in the information society, using information and communication technologies, and managing databases that facilitate informed policy- and decision-making.

Table 4. Innovation

| Discussion topic | Challenges | Opportunities | Good practices | |
|---|---|---|--|--|
| E-government In particular, about the level of engagement between Ministries of Health and e-government initiatives | Lack of legislation to ensure data protection; credibility issues Before the pandemic, health was not a priority within national egovernment initiatives Lack of a holistic understanding of the potential of digital transformation of the health sector | Collaboration with the private sector Building capacity for better policy dialogue Adoption of a monitoring and evaluation framework consisting of key performance indicators, as well as key objectives and outcomes for establishing, communicating, and periodically monitoring targets and outcomes in implementation of information systems for health | Digital governance structure where a health intelligence center can be linked to other areas of intelligence (economy, public safety, work) Use of standards for adopting emerging technologies that facilitate digital transformation in the health sector | |
| Digital literacy In particular, about the level of knowledge on new concepts such as artificial intelligence, blockchain technologies, and boot camps | Increasing access to technologies, but health personnel do not assimilate as quickly as needed Availability of training materials based on the realities of the countries, not generic packages | National authorities in constant dialogue with state and local governments Implementation of national digital literacy programs for the use of emerging technologies in public health | Production of communication guidelines and learning objectives that can reach different audiences | |

4. IS4H Plan of Action: Monitoring of Progress

As part of the actions carried out during the IS4H Conference, an exercise was conducted to monitor the progress of each indicator agreed with Member States for the Plan of Action for Strengthening IS4H 2019-2023 (see Annex 4). It was organized according to the four strategic areas of the plan, which will allow the continuing monitoring of and work on progress toward meeting the objectives to promote concrete solutions in support of IS4H in the Region. A detailed report is presented in Annex 5.

5. Strategic and Critical Thinking Report

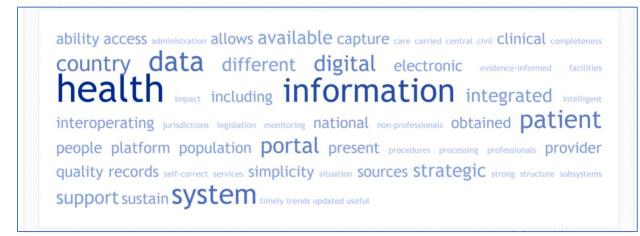
A strategic and critical thinking exercise was carried out during the two preparatory sessions of the IS4H Conference (see Figures 3 and 4). The following two questions formed the basis of the debate (see Figure 5).

Question 1

Imagine it is five years from now. What do other countries "admire" most about your country's IS4H?

Reflections from Member States

Figure 3. Tag Cloud Question 1: Strategic Thinking



- That the different jurisdictions of the country are interoperating electronic health records through a national digital health network and supported by patient portals.
- Digital transformation allowing total coverage for the population.

- A country that has electronic health records platforms linked from the central laboratory to at least three health facilities accessing data in real time; and without changing views with each new political administration.
- A patient portal platform to follow up to each patient across the country.
- Having an integrated health information system through all the different national health subsystems (including other sectors) with a strong governance structure and with sustainability strategies.
- That reliable information is available, the data obtained from different sources reflect
 the reality of the health situation; allowing operators to know the trends and distribution
 of health problems in the population, because information is available for health
 surveillance, planning, monitoring, strategic and operational evaluation of health
 management (for example, quality of health services, and the impact of the
 interventions carried out).
- There are clear rules and procedures that allow data capture, transmission, processing, and outputs, which allow information to be obtained in a timely manner, and this is useful for interested parties.
- Completeness, efficiency, and simplicity. There are no longer alternate or double registries. Personal data protection policies and the right to be forgotten and rectified are already a fact.
- Ability to respond to people everywhere under one single portal (patient portal).
- The quality and timeliness of the data, which allow the use of predictive models.
- Having a comprehensive and integrated information system, connectivity in all health establishments, and digital literacy of professionals and non-professionals who work in health.
- A seamless information system that captures information from public, private, and civil society providers as well as other sources of both clinical and strategic information. A system that is intelligent enough to self-correct and do analysis, including big data, and present patterns that will support and facilitate evidence-informed decisionmaking on clinical, strategic, or programmatic issues.
- The simplicity of integrating new information systems with the general health information system.
- A country with the ability to ensure that people's health information can be followed and available regardless of which health provider is treating them at a certain time, so that it can sustain and support the continuity of health care. Moreover, patients can access their own health information through the implementation of patient portals.
- A country with a health system that presents an important advance toward interoperability with the support of updated, modern, and safe legislation, with all its medical staff being digitally literate.

Question 2

As you envision where you want your country to be in 10 years on IS4H, what do you want to see being different?

Reflections from Member States

Figure 4. Tag Cloud Question 2: Strategic Thinking

```
ability (1) access (2) adjustments (1) algorithms (1) allows (2) based (1) clinical (2) contributed (1) COUNTRY (8) create (2) creation (1) data (4) decision (2) different (1) digital (2) disaggregation (1) electronic (2) encompasses (1) facilitates (1) full (2) guarantees (1) hacked (1) health (9) human (1) improve (4) information (9) integrated (2) interoperability (3) intersectoral (1) intra (1) knowledge (2) levels (1) management (4) maturity (2) model (4) patient (2) platforms (4) policy (2) population (3) portal (2) processes (2) protect (2) protocols (1) provide (1) quality (3) real (2) reflects (1) regional (1) research (3) sector (2) security (1) services (1) sources (1) strategic (1) supported (1) System (6) tools (2) user (2) values (1) various (1)
```

- A country where all patients have their own and cybersecure portal.
- Integrative and innovative tools that allow the maturity model to be surveyed in real time, and that through intelligent algorithms propose improvements and adjustments to the model in real time.
- A country with regional and district hospitals connected to real-time electronic health records platforms.
- That the country's digital health policy is of collective creation and reflects the needs of the people.
- Managers and decision-makers using the IS4H model and developing their strategic planning based on accurate and quality information to improve their health system performance and the health of the entire population.
- Being able to have integrated information in a place that is easily accessible to internal and
 external users of the system. That it broadly encompasses the determinants of health and
 serves to influence the decisions of the health sector and other sectors to improve the quality
 of life of the population with an adequate prioritization and equitable distribution of resources.
 Moreover, that the information obtained from different sources yields similar values. The
 system has contributed to promoting and improving research, teaching, and knowledge
 management.
- A strong focus on users/citizens and their rights over their information.

- Human talent with capacities to manage and use patient portal platforms.
- Being near the top in the maturity model, possibility of data disaggregation, and full interoperability across the country.
- A country achieving full interoperability in an intra- and inter-sectoral way. Quality data for the management of timely health information, supported by sustainable and scalable platforms for digital health.
- Data sharing is encouraged because data are protected without risk of being hacked or spread unscrupulously in an unethical manner. A unifying platform that allows for interoperability of disparate systems, allowing them to speak a common language. This is also a system governed by robust and feasible policies and protocols where there is oversight of the processes at various levels.
- A country with information systems that facilitate the population's access to health services and are really tools that streamline processes and not create barriers.
- A country with the ability to make clinical information that is handled in electronic form available also for clinical research, and for science and research more generally, and thus create more knowledge.
- A country that can provide guarantees on the treatment of information with information security measures to protect it.

Figure 5. IS4H Conference: Welcome Remarks Session 1



6. The way forward

From the perspective of the IS4H initiative, the year 2020 was characterized by "sharing, listening. and acting". Thus, it was that, working together with partners and strategic allies, the main spaces for improvement were identified. These are shown in the Table 5.

Table 5. Spaces for improvement

| What can be improved? | How? |
|--|---|
| Data management and information technologies | By adopting international standards for data management and interoperability |
| Management and governance | By adopting guiding principles, policies and official governance mechanisms for data and information management |
| Knowledge management and sharing | By implementing a digital literacy program as an ongoing mechanism to strengthen human resources skills to work within the information society |
| Innovation | By determining the maturity of countries' information systems for health as a first step in identifying gaps and needs |

Taking into consideration this after-action review, and considering the challenges and opportunities identified by Member States during the IS4H the Conference, PAHO will present a regional road map focused on collaboration, co-creation and monitoring of the following high-level actions:

- Ensure convergence between regional actions and the Global Strategy on Digital Health
- Strengthen governance mechanisms in support of digital transformation processes
- Expand collaboration with nontraditional partners, in particular with the telecommunications sector, legislators, and the information and communications technology industry
- Promote digital literacy and change management strategies at all levels
- Incentivize innovation

The Information Systems for Health (IS4H) Conference, From the Evolution of Information Systems for Health to the Digital Transformation of the Health Sector, aimed to create a dialogue of reflection with the countries of the Region of the Americas on their experiences regarding their information systems and digital health during the last four years, especially during the COVID-19 pandemic.

Discussions at the preparatory sessions focused on the strategic goals of the IS4H Plan of Action. The approximately 150 participants recognized the importance or working together with a common goal and under the eight principles presented by the Pan American Health Organization (PAHO) for the digital transformation of the health sector: (i) achieve universal connectivity in the health sector; (ii) co-create digital public health goods for a more equitable world; (iii) accelerate progress toward inclusive digital health; (iv) implement open, sustainable, interoperable digital information and health systems; (v) mainstream human rights across all areas of digital transformation in health; (vi) participate in global cooperation on artificial intelligence and any emerging technology; (vii) establish mechanisms for the confidentiality and security of information in the digital public health setting; and (viii) design a renewed public health architecture for the age of digital interdependence.

This report summarizes the discussions, agreements, and main conclusions of the conference, at which PAHO launched a call to action to position the health sector in the vanguard of digital transformation in public health in the Region.