Inclusive Digital Health

Eight Guiding Principles for the Digital Transformation of the Health Sector

Digital transformation toolbox
ORGANIZATION, COORDINATION, AND DEVELOPMENT

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Abstract

Inclusive digital health is one of the eight guiding principles for the digital transformation of the health sector promoted by the Pan American Health Organization (PAHO). This policy brief presents key concepts, recommended lines of action, and monitoring indicators, with the objective of advancing inclusive digital health.

According to its PAHO definition, this guiding principle is intended to accelerate towards inclusive digital health, with an emphasis on the most vulnerable:

Leaving no one behind in the digital age requires not only reaching populations in situations of greatest social, economic, geographic, or cultural vulnerability, but also people and population groups that are not digitally literate. Information and communications technologies (ICTs) have the potential to reduce health inequalities by allowing people to access information and digital tools for prevention and care at the right time and in the right format. Digital inclusion implies appropriate access, digital skills, and usability and navigability in the development of technological solutions. All this should encourage inclusion, while respecting the autonomy of individuals and groups who decide not to use digital services.

The application of ICTs in the field of health has been growing in recent years. However, multiple inequities in access to health systems and in digitalization strategies are still being detected in different communities. Leaving no one behind in the digital age requires reaching those populations in situations of greater social, economic, geographical, or cultural vulnerability, as well as people and population groups that lack digital literacy, encouraging the adoption of technologies, provided that people autonomously decide to use digital services.

With this approach in mind, PAHO has proposed lines of action that are detailed in this policy brief through implementation recommendations. Generally speaking, it is recommended that:

- The digital solutions developed and implemented in the field of health be accessible to members of the population with different motor, visual, auditory, or other abilities, including both users of the health system and professionals who use these applications
- Possible health gaps be assessed before technologies are adopted, so that computerization processes do not reinforce existing health inequalities
- Standardized protocols, rules, and regulations, and clear lines of action be developed to implement this principle
- Work teams ensure human and professional diversity, to favor the implementation of inclusive designs
- Digital systems and tools represent and refer to all individuals and social groups in an equal and non-discriminatory manner
- Monitoring indicators be used to assess the extent to which digital health projects are inclusive

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1 On 23 November 2021, in collaboration with PAHO, an asynchronous policy dialogue was convened to advance the implementation of the roadmap for the digital transformation of the health sector in the Region of the Americas. The participating experts identified points of reference for the topics addressed by the guiding principles.
• Actions to implement the principle of inclusive digital health be considered when designing digital agendas, so that they do not increase or deepen pre-existing inequalities in the population—one of the greatest challenges.

Keywords: inclusive digital health, digital transformation, guiding principles, health inequalities.
Introduction

According to the Pan American Health Organization (PAHO), it is essential to accelerate progress towards inclusive digital health, with an emphasis on the most vulnerable people.

Leaving no one behind in the digital age requires not only reaching populations in situations of greatest social, economic, geographic, or cultural vulnerability, but also people and population groups that are not digitally literate. Information and communications technologies (ICTs) have the potential to reduce health inequalities by allowing people to access information and digital tools for prevention and care at the right time and in the right format. Digital inclusion implies appropriate access, digital skills, and usability and navigability in the development of technological solutions. All this should encourage inclusion, while respecting the autonomy of individuals and groups who decide not to use digital services (1).

In recent years, different international organizations have stepped up calls for countries to strengthen their health systems through developing digital agendas that include implementing ICTs. The purpose of this strategy is to improve decision-making and evidence-based policymaking that address health inequities and advance the goal of universal health coverage and universal access to health (2, 3).

In the field of health, the growing use of ICTs skyrocketed exponentially during the COVID-19 pandemic. Because digital transformation is an irreversible reality, PAHO has developed an initiative that includes the Eight Guiding Principles for Digital Transformation of the Health Sector in the Region of the Americas, a call for action that urges Member States and institutions and workers in the sector to collaborate on coordinating technical and legal decisions that leave no one behind, so that ICT implementation ceases to benefit a minority and becomes the right of all. Additionally, it highlights the importance of public policies that incorporate digital literacy into the educational system from preschool onwards, ensuring that all initiatives related to digital transformation consider the ethical principles and foundations of inclusion and human rights (4).

This principle can be approached from both analytical and conceptual perspectives:

From an analytical viewpoint, inclusive digital health can be considered as revolving around the following three ideas:

1. **Accessibility:** Everyone can access digital health equitably, including the following:
   a. Connectivity, electronic devices (hardware), and applications based on improving health care (software)
   b. Possess digital skills that enable each person to use and understand digital tools
   c. Applications that incorporate usability and navigability rules into their design (5)

2. **Composition of work teams:** This point emphasizes that to comprehensively address the principle of inclusive digital health, it is extremely important to have diverse, interdisciplinary working groups and decision makers. Each member of the team will contribute a different, complementary perspective to favor the design, development, and implementation of inclusive information systems and technologies for health (6).

3. **Representativeness:** Defined as the capacity of digital systems and tools to represent and refer to all persons and social groups in an equal and non-discriminatory manner regardless of their gender, age, ethnic or cultural identity, beliefs or ideology, origin or nationality, socioeconomic situation, migratory status, health status, or any other condition, especially considering the inclusion of the most vulnerable groups (7).

From a **conceptual perspective**, the principle of inclusive digital health is understood as the intersection of three dimensions: **health, ICT or digital developments, and inclusion or diversities.**

It is well known that there is abundant scientific evidence about these dimensions taken in pairs: for example, health and inclusion, health and technologies, or technologies and inclusion. However, there is still little progress in the state of the art and the implementation of the concept of inclusive digital health as the intersection of all three of these dimensions taken together.
Indeed, health informatics does not, by itself, address many of the social factors that contribute to health disparities, and does not necessarily solve accessibility problems. Consideration should even be given to the possibility that the application of health technologies may unintentionally widen health inequalities, rather than reduce them (8, 9).

The purpose of this policy brief is to contribute to drafting concrete recommendations so that decision makers in the general area of health policy, and of digital health specifically, can begin to implement the principle of inclusive digital health, taking as a framework the lines of action proposed by PAHO.

This policy brief conceptually defines the principle of inclusive digital health, then describes the current status of its implementation and identifies the main obstacles and barriers for each of the lines of action proposed by PAHO. It continues with the main recommendations for implementing these lines of action, followed by a presentation of the suggested monitoring indicators, ending with some general recommendations.
Current status and identification of gaps

On a worldwide scale, international organizations such as PAHO are addressing the importance of the principle of inclusive digital health and the need to incorporate gender criteria, the intercultural perspective, and the principles of equity and solidarity into digital health actions and agendas. However, consideration of these issues at the level of these specific agendas remains incomplete, and usually includes only a few specific aspects involving the legal and regulatory frameworks to be implemented.

In addition to the inclusion of the principle of inclusive digital health in digital agendas, to undertake concrete actions it is important to identify people and social groups according to their degrees of vulnerability, particularly in digital matters, in order to have reference data that can serve as a starting point when formulating, and subsequently evaluating, interventions in the field of inclusive digital health, enabling them to focus on the populations that face the most inequalities. Of course, it is extremely expensive to detail the diversity of social groups in any given territory, owing to the complexity and dynamism of social structures, all of which have an impact on representativeness in information systems. Likewise, determining which groups suffer some type of vulnerability and measuring levels of vulnerability in general, and regarding the digital realm in particular, risks running into multiple biases associated with the measurement tools used and with the overrepresentation of people who can already effectively access health and information systems. Consequently, there is a certain lack of knowledge regarding population diversity, which generates a shortage in the quantity and quality of baseline data that can be taken as a starting point for formulating and evaluating interventions.

Moreover, in seeking greater knowledge about populations, it is not only of interest to identify their levels of vulnerability, but also to analyze the beliefs, concerns, and motivations regarding decision-making in the field of health that may affect the inclusion of digital health for all, taking into account the most vulnerable people.

In terms of the individuals in charge of making health policy and digital health decisions, applying this knowledge requires diverse, interdisciplinary teams, with different views and skill sets and with the ability to analyze constructs as complex as the beliefs, concerns, and motivations of people regarding their health, particularly when it comes to social groups with diverse ethnic and cultural origins.

Likewise, these teams and the users of health systems and information systems have different beliefs, interests, and motivations, which can generate information biases, given the distance between the patients who use the systems (their complexities or diverse characteristics) and the prototypes of the "digital citizen" that are the basis for designing computer systems. Furthermore, the lack of leadership in promoting inclusive digital health hinders the development of policies to foster collective awareness aimed at achieving equity among peoples and communities.

Another crucial issue when promoting specific actions is multisectoral coordination as a basic strategy for designing and implementing digital inclusion policies, such as awareness-raising campaigns and training programs for officials, health institutions, and the general public. While the importance of multisectoral actions is widely accepted, inclusive digital health initiatives are often fragmented and scattered among different sectors (such as the health and education systems, civil society organizations, and the private sector). This lack of coordination is usually due to several reasons, including the following: lack of...
common guidelines and high-level regulations; accelerated growth of technologies and of companies that develop digital solutions, but are unaware of the complexity of the health system; and lack of communication between different areas regarding the needs, interests, and particular objectives of each sector.

It is interesting to note here that the existence of a clear sense of urgency, as when the COVID-19 pandemic hit, represents a huge window of opportunity to achieve coordinated actions that have great health and social impact, leaving in their wake a level of integration that can serve as a basis for other health actions.

In line with this idea, a crucial action strategy for inclusive digital health is to empower individuals and their communities (such as children, youth, older people, gender-diverse people, people with different abilities, peoples of different ethnic origins) through initiatives that promote digital health. However, it is necessary to consider possible barriers to implementing such lines of action; firstly, owing to inequities in access to the Internet and electronic devices. Once this gap has been overcome, another barrier that must be considered is the degree of digital literacy of different populations. **In terms of both access and digital literacy, lack of inclusion affects the most vulnerable individuals and communities. Therefore, the implementation of digital health projects can cement access difficulties and pre-existing inequities.**

To empower individuals, it is important to promote the inclusion of people-centered digital health, ensuring that the population knows their rights and responsibilities regarding the security, privacy, and reliability of health data. This has been an issue for many years, regardless of the format of the data (whether electronic or on paper). Here, it is important to strengthen existing strategies, taking into account that, in general, people know very little about their rights regarding health in general, and those related to their health data in particular. This results in a gap between the ideal of the empowered patient and the diversity of those actually using health systems, who may be affected by different situations of vulnerability.
Lines of action

PAHO (1, 10, 11) has called for stakeholders to work, coordinate, and motivate to incorporate, strengthen, and ensure inclusive digital health, based on the following lines of action:

• Enable digital resilience so that health systems can continue to offer coverage when physical care becomes impossible, with special attention to the most vulnerable populations

• Use baseline data as a starting point to formulate and evaluate interventions, determining which people and groups live with some degree of vulnerability and their relationship with the virtual world

• Analyze the beliefs, concerns, and motivations involved in health decision-making that may affect the inclusiveness of “digital health for all” policies, taking into account the most vulnerable people

• Incorporate gender criteria, the intercultural perspective, and the principles of equity and solidarity into actions related to the digital health inclusion agenda

• Promote the inclusion of people-centered digital health, ensuring that the public is aware of their rights and responsibilities regarding the security, privacy, and reliability of health data

• Undertake multisectoral actions to formulate and implement digital inclusion policies and strategies, such as awareness campaigns and training programs targeting officials, providers, and the general public

• Empower individuals and their communities (children, youth, the elderly, women, people with disabilities, and indigenous peoples) through initiatives promoting digital health

Taking as a guide the lines of action prioritized by PAHO and the recommendations provided by the experts consulted, a series of actions are proposed below. However, considering the heterogeneity of the countries of the Region, these recommendations must be adapted to the reality of each country, including its degree of maturity and the resources available.

Considering the different levels of management in the digital transformation of the health sector, the following is recommended for each one:

• **High-level or upper management**: The digital agendas of the countries should be aligned with the recommendations of international organizations and take into account, from their own viewpoint, the principle of inclusive digital health at the same priority level as the other principles related to digital health. It is essential that they be able to promote and support the advancement of regulatory frameworks.

• **Mid-level or middle management**: People in decision-making positions in digital health should include this principle in their operational plans, as well as allocate the necessary resources for its implementation. They should also be responsible for fostering diverse, interdisciplinary teams, with different perspectives and capacity for dialogue.

• **Low-level or lower management**: Those who implement projects and work on the design and implementation of information systems should take into account the representativeness of population diversity in health information systems to inform decision-making. They should also encourage the participation of people and community representatives in projects based on inclusive design, contributing to accessible solutions.

Governments should consider including universal connectivity in their national plans and strategies for universal health access and coverage through recommendations, guidelines, technical specifications, regulations, plans, assessment instruments, good practices, standards, and indicators.

The following are the specific lines of action proposed:
1. ENABLE DIGITAL RESILIENCE SO THAT HEALTH SYSTEMS CAN CONTINUE TO OFFER COVERAGE WHEN PHYSICAL CARE BECOMES IMPOSSIBLE, WITH SPECIAL ATTENTION TO THE MOST VULNERABLE POPULATIONS

Recommendations:

- Promote the declaration of connectivity and access to the Internet as universal rights
- Strengthen the role of the government as the guarantor of universal access to the Internet and promote the coordination of agreements between the public and private sectors, generating incentives and facilities for investment in infrastructure in remote or low-connectivity areas
- Facilitate access to devices and develop or update online programs and services, taking into account ease of use and navigation
- Urge digital service providers to ensure the proper functioning of their services and to develop clear and robust contingency systems

2. FORMULATE AND EVALUATE INTERVENTIONS, DETERMINING WHICH PEOPLE AND GROUPS LIVE WITH SOME DEGREE OF VULNERABILITY AND THEIR RELATIONSHIP WITH THE VIRTUAL WORLD

- Create interdisciplinary teams to develop tools for collecting and recording population data that include cultural, ethnic, socioeconomic, religious, gender, and health information
- Consider the different sources of existing data generated by other agencies or sectors (including population censuses and national or subnational surveys on health, socioeconomic situation, and education)
- Define levels of vulnerability regarding access to digital health according to the different dimensions identified and sources considered; establishing these definitions in coordination with community members, considering their viewpoints and convictions, brings greater value
- Understand and consider identities, heterogeneity of local situations, and different levels of vulnerability when planning, implementing, and subsequently, evaluating digital health interventions
- Regularly update these reference data in line with ongoing social developments at the local level
- Promote studies that explore the needs and perceptions of different population groups regarding health decision-making

3. ANALYZE THE BELIEFS, CONCERNS, AND MOTIVATIONS INVOLVED IN HEALTH DECISION-MAKING THAT MAY AFFECT THE INCLUSIVENESS OF “DIGITAL HEALTH FOR ALL” POLICIES, TAKING INTO ACCOUNT THE MOST VULNERABLE PEOPLE

Recommendations:

- Encourage the creation of interdisciplinary teams (including professionals from the social sciences and education) with diverse training histories to lead and work on digital health projects, promoting these teams’ capacity to implement the principle of inclusive digital health
- Address the principle of inclusive digital health in undergraduate, postgraduate, and ongoing health informatics training programs
- Promote studies that explore the needs and perceptions of different population groups regarding health decision-making


Recommendations:

- Develop computer systems where the identification or registration of people (when opening a digital health history or electronic health records) does not involve such mandatory requirements as presenting documentation to prove identity, using, for example, the validation of biometric data, and considering a contingency system for people without documentation or when biometries are not available, ensuring equity in access to health care
• In computer systems where the identification of persons involves recording personal data, only those fields necessary for opening the health history should be included, without recording such personal choices as beliefs or sexual orientation, and recording only the data necessary for identification, considering in a non-discriminatory manner such elements as gender diversity, cultural identification, or any other condition of the person (e.g., family, immigration status, housing, nationality).

• Incorporate different fields for recording the sex assigned at birth and the gender of each person, providing variables that make it possible to represent diversity, taking into account the possible amendments and additions that could arise.

• Incorporate fields for registering the name assigned at birth and the self-assigned name in terms of gender.

• Consider the option of recording nationality and different cultural identities or ethnicities.

• Consider the option of registering multiple perceived identities associated with the same person.

• Consider the possibility of extended and unconventional kinships, because not all societies or groups are structured around univocal relationships such as mother or father.

• Consider the possibility of recording as someone’s residence non-conventional categories such as shantytowns, informal settlements, and remote rural areas, including the possibility of registering people living in the streets.

• Develop a system for recording health status or health history that takes into account gender diversities and cultural identities.

• Provide accessible resources within the computer system (e.g., dictionaries or icons) that include key health terms in the languages of the user populations, to guarantee equitable access to health.

• Create good practice guides targeting professionals who provide care for sexually diverse people or people with diverse beliefs about health.

• Ensure that the terminologies, vocabularies, or classification systems for diseases, diagnoses, and health problems or situations used by the computer systems include, in a non-discriminatory manner, the diversities of gender, cultural identity, or any other condition of the person.

5. PROMOTE THE INCLUSION OF PEOPLE-CENTRED DIGITAL HEALTH, ENSURING THAT THE PUBLIC KNOWS ITS RIGHTS AND RESPONSIBILITIES REGARDING THE SECURITY, PRIVACY, AND RELIABILITY OF HEALTH DATA

Recommendations:

• Promote regulations on the rights of people to the security, privacy, and confidentiality of their health data, considering the characteristics of data in electronic formats.

• The entities that have custody of people’s health information must ensure that only these people can authorize the storage of and access of third parties to their data.

• These same entities must likewise ensure that each person can access their own data and share it whenever necessary.

• Entities that develop programs or applications must comply with regulations guaranteeing individuals’ rights over their health data.

• Entities that develop programs or applications must promote user-centered design strategies to ensure inclusive design that takes into account human diversity from the beginning of these projects, and they should consider recommendations to ensure the web accessibility of their products.

6. UNDERTAKE MULTISECTORAL ACTIONS TO FORMULATE AND IMPLEMENT DIGITAL INCLUSION POLICIES AND STRATEGIES, SUCH AS AWARENESS CAMPAIGNS AND TRAINING PROGRAMS TARGETING OFFICIALS, PROVIDERS, AND THE GENERAL PUBLIC

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2 This applies countries where ethnicity is perceived in terms of a social group within a unified Nation State, and also to cases of plurinational States, such as the Plurinational State of Bolivia, where the cultural identity of each person, if desired, is included together with Bolivian citizenship on their identity card, passport, or other legally valid identification documents.

3 An example is the case of implementation of a health information system in Kenya, where the unique identification of persons was a requirement for the use of electronic medical records, in a social context where the lack of persistent personal identifiers is socially valued and where the practice of using different identities according to the purpose is common (2, 5).
Recommendations:

- Form heterogeneous working groups, featuring representatives from different sectors including experts in health informatics, legitimate community representatives, members of civil society organizations and health workers from diverse backgrounds

- Promote the general public’s digital skills through multisectoral strategies, with special emphasis on the coordination between health, education, and digital service providers, and focusing on those groups most affected by the digital divide, generating specific programs for different segments of the population (older adults, young people, indigenous peoples, and people with some type of disability)

- Incorporate digital skills into the educational system from preschool onwards, and carry out campaigns that reach different age and social groups

- Ensure access to information on digital health products that is clear, understandable, and adapted to each group of people according to their degree of digital literacy

7. EMPOWER INDIVIDUALS AND THEIR COMMUNITIES (CHILDREN, YOUTH, THE ELDERLY, WOMEN, PEOPLE WITH DISABILITIES, AND INDIGENOUS PEOPLES) THROUGH INITIATIVES PROMOTING DIGITAL HEALTH

Recommendations:

- Form work teams on digital health that prioritize communities and territories where there is greater inequity, with a view to reducing digital and access gaps

- Implement an inclusive design strategy by involving different groups and individuals in the design process, considering human diversity from the beginning of any project, and taking into account recommendations to guarantee products’ web accessibility

- Develop and make available to the community information systems that favor contact between individuals and their health providers, such as electronic personal health portals, telehealth strategies, and gamified applications, offering a variety of services, such as booking appointments, consulting study results, communication with professionals, co-registration of health data, and user-friendly interfaces

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4 Gamification means incorporating typical elements of game-playing into digital applications to improve their user-friendliness.
Monitoring indicators

With the aim of advancing the development and scaling up of inclusive digital health, the following indicators are proposed. It is important to clarify that this is not an exhaustive list, but that each country or region can include other indicators, and define the level of disaggregation and frequency of measurement necessary.

CROSS-CUTTING INDICATORS TO THE EIGHT GUIDING PRINCIPLES FOR THE DIGITAL TRANSFORMATION OF HEALTH

• National digital health strategy established through a regulatory framework

• Governmental organization structure to lead the digital transformation in health strategy

• Budget for a digital agenda that includes human resources and the necessary technology

SPECIFIC INCLUSIVE DIGITAL HEALTH INDICATORS FOR EACH LINE OF ACTION

1. Enable digital resilience for health systems

• Percentage of the population with access to the Internet (discrimination regarding access from home, work, school, or others)

• Number of electronic devices (personal or laptop computers, tablets, smartphones) per household

• Degree of development of contingency systems in digital health programs (low, intermediate, or high)

2. Use baseline data as a starting point for designing and evaluating interventions

• Population survey and analysis tools that include cultural, ethnic, socioeconomic, religious, gender, and health data (yes/no; if yes, percentage of penetration)

• Degree or percentage of participation of different sectors in designing survey tools or contributing data on the population and its relationship with the digital world

• Number of monitoring actions to track the evolution over time of the vulnerability parameter of defined groups, evaluating the effectiveness of interventions

3. Analyze beliefs, concerns, and motivations regarding decision-making in the field of health that may affect the inclusiveness of digital health

• Number of interdisciplinary teams leading digital health projects

• Degree of awareness regarding the principle of inclusive digital health among decision makers

• Percentage of training programs in health information systems that address aspects related to inclusive digital health

4. Incorporate gender criteria, the intercultural perspective, and the principles of equity and solidarity

• Number of jurisdictions or sectors whose digital health agenda includes criteria and actions related to the inclusive digital health principle
• Percentage of health information systems whose identification modules address aspects related to gender and cultural issues

• Percentage of electronic health records that allow the recording of data that takes into account gender, cultural, and ethnic diversities, among others

5. **Promote the inclusion of people-centered digital health, ensuring that the public knows its rights and responsibilities**

• Percentage of jurisdictions with regulations about the right of individuals to the security, privacy, and confidentiality of their health data

• Percentage of providers of health systems or services that guarantee compliance with regulations

• Percentage of health applications or content adapted for people with disabilities

6. **Undertake multisectoral actions to design and implement digital inclusion policies and strategies**

• Level of training diversity of work teams in health information systems, and representation of different capacities (none, low, moderate, high)

• Percentage of training programs that include aspects related to information systems and digital health, according to educational level

• Degree of multisectoral participation in digital inclusion campaigns involving health

7. **Empower individuals and communities**

• Number of work projects on digital health aimed at bridging digital and access divides

• Number of work projects on digital health that implement participatory design strategies involving diverse end-users

• Percentage of health providers offering digital solutions that promote closer relations with the community

• Level of access to digital solutions of people with some type of disability, people of different nationalities or origins, people with different gender identities, and with other diversities (none, low, intermediate, high)

• Percentage of people who accessed training in digital skills over the last year
General recommendations

In general terms, it is important that high-level decision-making and countries’ digital agendas be in line with the recommendations of international organizations, and that they take into account, from their own viewpoint, the principle of inclusive digital health. At the middle or mid-management level, people in decision-making positions in the field of digital health have the responsibility of fostering diverse, interdisciplinary teams, with different perspectives and capacity for dialogue. Finally, at the level of people who implement projects and work on the design and deployment of information systems, the representativeness of diversity in health information systems must also be considered.

In addition, at all levels, the following should be taken into account:

- Development of digital health solutions that are accessible to groups in the population with different motor, visual, auditory, or other abilities, whether they are users of the health system or professionals who use its applications

- Health gaps that precede the deployment of these technologies, so that computerization processes do not cement existing inequalities in health

- Creation of standardized protocols, rules and regulations, and clear lines of action for the implementation of the principle of inclusive digital health

- Generation by consensus of monitoring indicators to assess the extent to which digital health projects are inclusive

- Promotion of the implementation and periodic sharing of monitoring indicators between the different digital health projects

- Creation of mechanisms for periodic review of the agreed indicators to adjust them or propose new ones


