

Management of patient information

Trends and challenges
in Member States

Based on the findings of the
second global survey on eHealth

Global Observatory for
eHealth series - Volume 6



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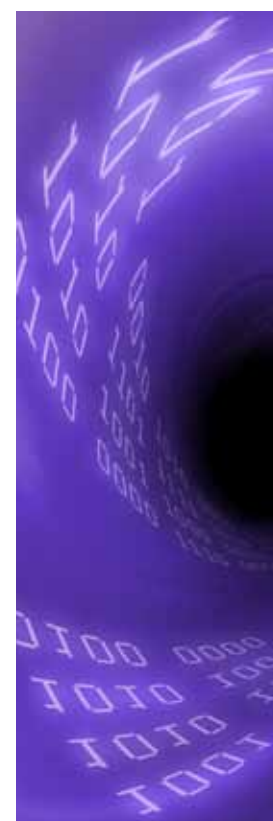
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Executive summary



Information and communication technologies (ICTs) have great potential to improve health in both developed and developing countries by enhancing access to health information and making health services more efficient; they can also contribute to improving the quality of services and reducing their cost. Patient information systems, for example, have the ability to track individual health problems and treatment over time, giving insight into optimal diagnosis and treatment of the individual as well as improving the delivery of services. This is particularly useful for chronic diseases, such as diabetes and cardiovascular diseases, and for maternal and child health services where a record of health and treatment over a period of time is required. Analysis of data in patient information systems can lead to new insight and understanding of health and disease, both chronic and acute.

Over the past decades, there have been great advances in ICTs for health, and the World Health Organization (WHO) has responded by establishing the Global Observatory for eHealth (GOe) to assess the adoption of eHealth in Member States as well as the benefits that ICTs can bring to health care and patients' well-being. To that end, the second global survey on eHealth was launched in late 2009, designed to explore eight eHealth areas in detail.

This, the final report in the Global Observatory for eHealth Series, assesses the results of the survey module that dealt with the patient information. It examines the adoption and use of patient information systems in Member States and reviews data standards and legal protection for patient data. The survey results – provided by WHO region, World Bank income group, and globally – showed that electronic information systems are being increasingly adopted within health settings; while this is seen primarily in higher-income countries, emerging economies such as Brazil, China and India, for instance, are also beginning to introduce electronic medical records (EMRs) into their health systems.

Low-income countries, however, have struggled to initiate large-scale electronic medical record systems. While some low-income countries have been able to attract technical and financial resources to install patient information systems at some sites, these require significant investments for their successful implementation. In fact, these systems require abundant resources including skilled labour, technological, and financial means, all of which can be difficult to procure in low-income settings. Further, patient information systems designed for high-income country health systems may not be appropriate in low-income countries. In particular, internationally-harmonized clinical models and concepts are needed for data interoperability and standardized international case-reporting, which could mitigate discrepancies between systems. The International Organization for Standardization's Technical Committee on health informatics ISO TC 215, for example, has developed an eHealth architecture that incorporates levels of maturity into the components of a health system to address these differences in requirements and capacity.

Of course, these issues are only relevant to electronic patient information systems. While use of such systems is increasing, many Member States still rely on paper-based systems for health data collection. The survey data analysed by WHO region showed that all regions have a high use of paper-based systems, particularly the African Region and South-East Asia Region. Countries within the Regions of the Americas, Eastern Mediterranean, and the Western Pacific reported a higher use of electronic transmission of health records than computer use to collect health data. This may be due to the use of fax or scanned image technology where the communication is electronic but the origin and destination are paper.

The use of electronic systems is higher for aggregated (summary) data than individual patient data. This could be because there is an institutional need for the aggregate data at management levels which in turn stimulates the creation of an electronic system. There may be a perception that individual patient data in electronic format may not be of as much value for administration, particularly given the difficulty of implementing patient information systems in general. However, the value of individual patient data for improved patient care is very much a case of 'connect the dots': given that many patients receive services from separate facilities and care providers, some form of electronic record system could compile these data and make them accessible to other health care professionals, leading, for example, to early detection of an influenza outbreak.

Electronic health systems must be built in a way to facilitate the exchange of data; disparate systems using separate disease definitions, for example, are of little value. Standards must be applied to the data and the systems themselves to allow for and facilitate the exchange of data between various sources. The adoption of standards is progressing well across most Member States including standards for eHealth architecture, data, interoperability, vocabulary, and messaging. These are important foundation blocks for the implementation of patient information systems because they facilitate clear communication. In addition, most countries have taken steps to establish legal frameworks for the protection of patient data.

The report concludes with an overview of steps Member States can take to facilitate the implementation of patient information systems. These include adoption of open source, standards-based software platforms and data exchange standards to make efficient use of existing resources. In addition, there needs to be clear legislation governing patient privacy and protecting the security of health information for records in electronic format. Finally, the development of well-trained health informatics professionals should be a priority.



1

Introduction



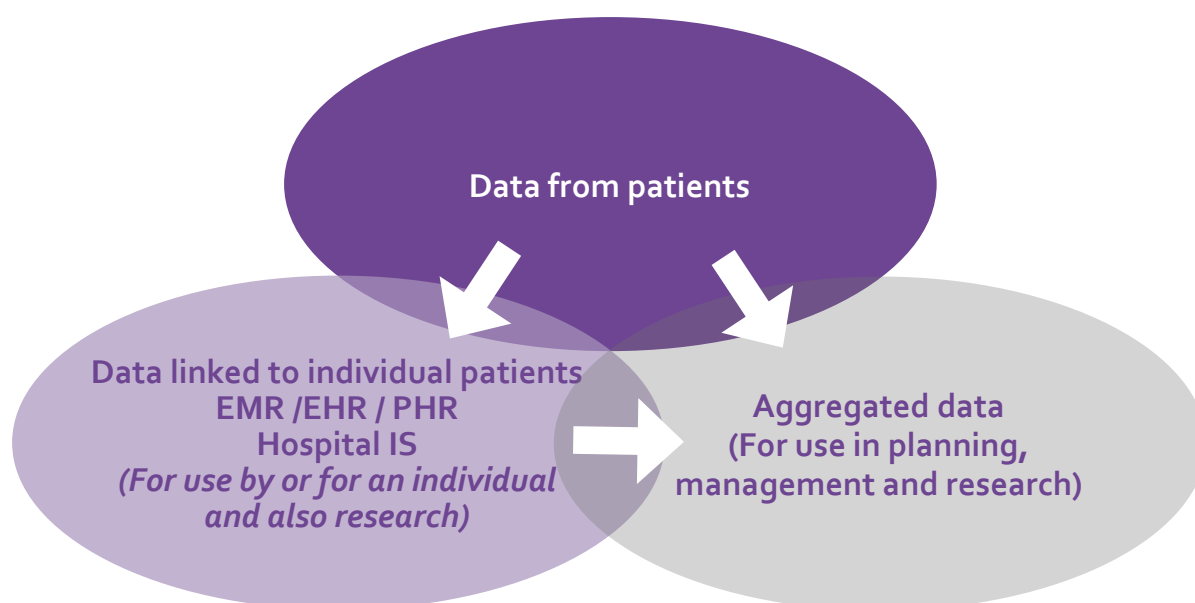
As part of its ongoing objective to the improvement of health through information and communication technology (ICT), the Global Observatory for eHealth (GOe) of the World Health Organization (WHO) conducted an extensive eHealth survey in 2009 which included a module on the management of patient information in Member States.

While a significant amount of health data comes from the community and environmental observations, a great amount of valuable detailed health data originates from patients in their encounters with health professionals. In addition, surveys and surveillance activities collect more data from and about individuals.

The key to effective patient information systems is to retain the link between the individual and the data collected over time and to make those data available to multiple health care providers when needed. Following this 'data trail' that charts the health of an individual is both valuable and important: these data can be aggregated to provide data trails for communities, regions, and countries, upon which public health policy is shaped. This includes resource management, monitoring and evaluation, disease surveillance, and operational research (as shown in the flow diagram below).

Many health information systems do not in fact retain data in the form of an individual patient record. Instead the data are aggregated into summary totals which obscure the individual patient link, making it difficult to follow patients over time. One of the reasons for this is that systems that collect, manage, and display individual patient data can be difficult to implement – particularly in low-resource settings, where health budgets are already strained.

Most health systems collect at least some individual patient data during clinical face-to-face encounters. Keeping these data personalized rather than anonymous is facilitated by using electronic systems which can more easily store, access, analyse, and share data. While the conventional way to collect such data are on paper forms and register books, increasingly, face-to-face encounters are being captured electronically. This trend will continue as improvements are made in computer hardware, software, and telecommunication infrastructure and as countries develop the skills necessary to implement electronic data storage and transmission systems. This report charts this progress – the evolution from paper-based to electronic records.



Part of the eHealth series based on the second global eHealth survey, this report is aimed at professionals in health care policy, planning, and management to help them understand the role of individual patient information systems, the current state of their deployment, and the issues in their implementation and use. A literature review of electronic patient information is followed by detailed analysis of the survey results. The survey covers individual and aggregate patient information at the local, regional, and national levels. The promising area of mobile health patient information is also covered. The foundation area of adoption of standards including existing international standards as well as national efforts to use these standards and national implementation efforts is discussed. This leads to important insights about eGovernment, eHealth and eHealth strategy. The final section uses the survey results as a lens through which to develop a framework for action to improve the effective use of patient information systems.

A note on terminology

Some people use the terms 'electronic medical record' (EMR) and 'electronic health record' (EHR) interchangeably. In fact there is a general level of confusion over the difference in the health sector in most countries due to overall lack of clarity by policy-makers, health professionals, and consultants; the fact that there are no standardized and accepted definitions across the sector furthers the confusion. The following definitions have been selected on the basis of their clarity and comprehensiveness.

An electronic medical record (EMR) is a real-time patient health record with access to evidence-based decision support tools that can be used to aid clinicians in decision-making. The EMR can automate and streamline a clinician's workflow, ensuring that all clinical information is communicated. It can also prevent delays in response that result in gaps in care. The EMR can also support the collection of data for uses other than clinical care, such as billing, quality management, outcome reporting, and public health disease surveillance and reporting.

Furthermore, an EMR may contain clinical applications that can act on the data contained within its repository, for example, a clinical decision support system (CDSS), a computerized provider order entry system (CPOE), a controlled medical vocabulary, or a results-reporting system. In general terms, EMRs are clinician-focused in that they enhance or augment the workflow of clinicians or administrators. EMRs are said to be interoperable if they are able to exchange data using standardized data transmission formats (1).

The electronic health record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports. The EHR automates and streamlines the clinician's workflow. It has the ability to generate a complete record of a clinical patient encounter – as well as supporting other care-related activities directly or indirectly via an interface – including evidence-based decision support, quality management, and outcomes reporting (2).

A third type of record and one which is controlled and managed by the citizen is the personal health record (PHR). It is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and eHealth tools. The PHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations (3).

Patient Information

Name (Last, First, Middle) _____

Date of Birth _____

Medical Record Number _____ Sex _____

Referring Physician Information

Name (To whom the original report will be mailed) _____

Hospital _____ Dept/Room _____

Street _____ City _____ State _____ Zip _____

Phone _____

Fax(es) (To which results will be sent) _____

Invoices will be directed to the Referring Lab, unless complete information is provided. We cannot accept government orders.

Sample Information (Only one sample type per test)

COLLECTION DATE (REQUIRED) _____

*** ADVANCE SCHEDULING REQUIRED FOR**

B - ACD Blood for Lymphocytes

F - Skin Fibroblasts (Mycoplasma Testing REQUIRED)

☐ Mycoplasma

Sample Types:

P - Plasma

U - Urine

H - Heart

L - Liver

CPT Codes and Price List for details

Assay

Carnitine (CN)

Carnitine

Acylcarnitine

Carnitine Ac

Carnitine A

Carnitine A

Carnitine A

Diagnosis is REQUIRED before sample can be tested (check all that apply)

☐ 277.87 Mitochondrial disorder

☐ 277.8 Metabolic disorder

☐ 359.9 Myopathy

☐ 783.4 Developmental delay

Other (ICD-9 codes) _____

Referring Lab Info

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

Fax _____

Clinical Summary attached ☐

☐ 276.2 Lactic acidosis

☐ 781.3 Hypotonia

☐ 780.39 Seizures

☐ 783.41 Failure to thrive

2

Patient information systems in the literature



Electronic patient information systems have the potential to improve health by giving health professionals improved information about their patients. They can also improve the quality of health care and help control costs through improved efficiency. The literature review covers health information systems with an emphasis on the management of patient information and will help contextualize the survey results. In particular it considers issues relating to the transfer of patient information from paper-based records to digital.

2.1 Maturity and adoption models

A number of models have been developed to help assess or describe the current level of information technology adoption in the health sector. These are useful benchmarks when looking at patient information systems.

Capability Maturity Model

The Capability Maturity Model (CMM) (4) was originally defined for software development by Carnegie Mellon University and is useful for assessing health information systems. Five levels are defined along the model's continuum. Predictability, effectiveness, and control of an organization's software processes are believed to improve as the organization moves up these five levels.

- **Level 1.** Initial (chaotic, ad hoc, individual heroics) – the starting point for use of a new process.
- **Level 2.** Repeatable – the process is able to be used repeatedly, with roughly repeatable outcomes.
- **Level 3.** Defined – the process is defined/confirmed as a standard business process
- **Level 4.** Managed – the process is managed according to the metrics described in level 3, that is, data collection and analysis.
- **Level 5.** Optimized – process management includes deliberate process optimization/improvement.

Enterprise Architecture

An alternative method is the Enterprise Architecture (EA) approach.¹ An early description of this methodology was described by Spewak and Hill (5), which is best adopted at the highest level, 'enterprise'. Although now twenty years old, the publication is still considered a foundation text in its field.

In order to implement the Enterprise Architecture process, the organization must first establish the preliminary framework and principles, a requirements management process, and governance. After the requirements and governance are established, EA focuses on a continuous cycle of improvements. The steps of this process are: architecture vision, business architecture, information system architecture, technology architecture, opportunities and solutions, migration planning, implementation governance, and architecture change management. This continuous cycle is the key to successful information system improvement in this process.

Australian National eHealth Interoperability Maturity Model

Individual health information must follow the patient as s/he receives services from various providers. This requires data interoperability which is the key to effective use of health information. The Australian National eHealth Transition Authority has defined an Interoperability Maturity Model (6) that identifies increasing capability for data interoperability.

Interoperability Maturity Model levels

- **Initial:** There is an early awareness of eHealth interoperability requirements and characteristics and perhaps some initial eHealth interoperability solutions adopted, typically localized within certain clinical or administrative domains.
- **Managed:** An organization will begin accomplishing some interoperability goals, such as the adoption of specific eHealth standards while gaining an early, shared understanding of data services or internal processes as well as initial governance established to ensure repetition of earlier successes.
- **Defined:** An organization has defined a set of guidelines for the adoption of eHealth standards for data, services and processes, according to the lessons learnt from previous maturity levels. Communication standards for interaction with internal and external partners are established, facilitating a shared understanding across technical and semantic issues.

¹ See for more information, <http://enterprise-architecture.info/> and <http://www5.opengroup.org/togaf>

- **Measured:** An organization has established processes for appraising and measuring eHealth interoperability.
- **Optimized:** The organization has implemented processes to support continuous interoperability improvements, driven by feedback from monitored processes.

The Australian Interoperability Maturity Model closely follows the Capability Maturity Model which makes it logically consistent in application.

The HIMSS EMR Adoption Model

This model relates to the management of patient information and was developed by the United States-based Healthcare Information and Management Systems Society (HIMSS).²

The HIMSS Electronic Medical Record Adoption Model (7) describes the stages from 0 to 7 of EMR adoption within organizations. It starts with laboratory, radiology and pharmacy and progresses to document imaging, clinical documentation and protocols, and medications. Since it is based on a hospital environment, some of the steps may not be appropriate for outpatient care models.

- **Stage 0:** Some clinical automation may be present, but all three of the major ancillary department systems for laboratory, pharmacy, and radiology are not implemented.
- **Stage 1:** All three of the major ancillary clinical systems (pharmacy, laboratory, radiology) are installed.
- **Stage 2:** Major ancillary clinical systems feed data to a clinical document repository (CDR) that provides physicians access to results.
- **Stage 3:** Clinical documentation (e.g. vital signs, flow sheets) is required.
- **Stage 4:** This includes a CPOE along with the second level of clinical decision support capabilities related to evidence-based medicine protocols.
- **Stage 5:** The closed loop medication administration environment is fully implemented in at least one patient care service area.
- **Stage 6:** Full physician documentation/charting (using structured templates) is implemented for at least one patient care service area.
- **Stage 7:** The hospital has a paperless EMR environment. Clinical information can be readily shared via electronic transactions or exchange of electronic records with all entities.

The HIMSS model was developed for hospitals in the United States of America so reflects the way medicine is practiced there and assumes adoption of specific standards such as the Clinical Document Architecture (CDA) standard.³ Note that at the end of 2010, only 1% of hospitals (approximately 57) in the United States had reached stage 7 of the EMR adoption model (8). No hospitals in Canada had attained that level of development (9). Although the model may be applicable to other countries it would require adaptation to country conditions and national standards.

² www.himss.org

³ http://www.cdc.gov/nhsn/CDA_eSurveillance.html

2.2 ICT in developing countries

Developing countries usually collect district level aggregate health data to plan and manage their health systems. After they have established district level health data collection, these countries may move to more complex data systems including patient information systems, which rely on ICT infrastructure. ICTs can help developing countries make better use of limited resources to improve health by providing better use of information. Studies are presented here which give some insight into the factors for success of ICTs in developing country contexts.

The Gates Foundation sponsored a comprehensive analysis on the state of health information systems in developing countries that was published in 2009 (10). It explored systems in 19 developing countries (three of which received an in-depth analysis). Five stages of increasing sophistication of health technology were defined. The first three focus on the development of the district health information system from manual (level 1) through optimized (level 2) and electronic reporting (level 3). Level 4 incorporates operational health ICT systems such as EMR, pharmacy, laboratory, automatic data capture and access to information. Their top level is a fully integrated national health information system, which includes data from all public and private sources.

Results showed that most of the 19 countries selected only collected district level information, 6 of which were at level 1 (manual); 7 had started to integrate level 2 (optimized) or level 3 (electronic reporting). Only 4 countries had firmly integrated level 3, and only 2 (Belize and Brazil) were utilizing level 4 by implementing EMRs.

infoDev has also assessed the use of ICT in developing countries. Its 2007 framework paper (11) examines areas of successful ICT use, factors for these successes, and the issues that need to be considered in each intervention and setting. The paper identified a number of issues that must be carefully considered in the local context. These include a health sector structure and regulatory framework providing openness to collaboration; clearly defined goals, action plans, and potential outcomes and benefits; mechanisms for coordinating action led by the public sector that includes public, private, and social efforts; the state of telecommunications reform and availability of affordable ICT access; presence of data standards and regulatory frameworks; mechanisms to develop the capacity of health workers; and options to ensure the continuity and sustainability of the effort.

From these observations, the researchers make several broad conclusions about adoption of ICTs in the health sector. First, keep the technology simple, relevant, and local. Build on what already exists and is being used. Second, involve users in the design by demonstrating benefit. It is always useful to develop and strengthen capacity through training to use, work with, and develop effective ICTs. It is useful to design a communication strategy with the ICT project to ensure that everyone understands what is being done and why to foster support. infoDev has also created a continuously updated database to function as an ongoing resource for stakeholders.⁴

Although the lessons discovered from the work of the Gates Foundation and infoDev were all drawn from developing countries with the goal of providing guidance on what works and how, many of these lessons apply equally to developed countries.

⁴ http://www.asksourc.info/res_library/ict_infodev.htm

2.3 Benefits of electronic health records

EHR systems are complex applications (12) which have demonstrated benefits. Their complexity makes it imperative to have good application design, training, and implementation. Studies have evaluated EHR systems and reported on various benefits and limitations of these systems (13–15). Benefits included increase in immunization rates, improved data collection, increased staff productivity, increased visitor satisfaction with services, improved communication, quality of care, access to data, reduced medical errors, and more efficient use of staff time. Some of the disadvantages noted were: time-consuming data entry, slow access of data and decreased quality of patient-doctor interaction.

The WHO Western Pacific Region published the *Medical Records Manual: A Guide for Developing Countries* which provides extensive information on the characteristics of medical records and related policies and procedures. It contains a section dedicated to EHRs (16).

In recent papers, McKay, Douglas and colleagues (17, 18) document their experience implementing clinical workstations at the point of care in Malawi. They designed and built an innovative hardware and software system using touch screen clinical workstations which collected individual patient information, analysed the data and presented information on national protocols. They demonstrated that the system could efficiently and accurately guide low-skilled health care workers through the diagnosis and treatment of patients following national protocols. The system captured and presented clinical data that supplemented clinical decision-making. In addition, the data were aggregated and used at the national level for policy-making and analysis. In 2010, a total of 650 000 patients were registered with 50 000 receiving care for human immunodeficiency virus (HIV).

The systems were used for patient registration, HIV care, paediatric patient management, radiology, pharmaceutical and laboratory work. They used free open-source software for the project which enabled them to enlist the support of a large community. The success of this programme was demonstrated by improved quality of care and a high level of acceptance by clinical workers.

EMR systems are available from both closed proprietary systems developed and supported by private enterprise and also in the form of free open source software systems which are supported by non-profit-making organizations and private enterprises. Open source systems have advantages of local sustainable community development and support and lower cost by building on a proven software foundation (19).

Improvements in quality have been demonstrated by increased adherence to guideline-based care, enhanced surveillance and monitoring, and fewer medication-related errors, such as incorrect prescriptions involving the wrong drug, wrong dose or incorrect route of administration. Other areas that show improvements are efficiency and reduced costs related to utilization (reduced numbers of laboratory and radiology tests), improved drug dosing and decreased medication related adverse events. Personal history records have additional potential benefits to improve patient health and communication with providers (20).

Studies have shown improvements in health information technologies increasing adherence to guideline or protocol-based care (21) and clinical decision support (22). EHRs have been shown to improve the quality of diabetes care (23).

Another area of demonstrated improvement is in the increased coverage of preventive care services such as influenza vaccination, pneumococcal vaccinations and faecal occult blood testing (24).

Individual patient information is often aggregated for monitoring and evaluation functions or reporting to higher management levels. However, aggregated individual patient information is also valuable in the local context where it can help to establish a 'culture of improvement', i.e. to measure quality of services and outcomes and use this to introduce changes.

2.4 mHealth

The use of mobile technologies for data collection about individuals and interactive information services are a part of a growing area of eHealth called mHealth. The GOe published a volume on this subject in 2011 (25) which documents the uptake of mHealth worldwide by types of initiatives and main barriers to scale. Mobile technologies are emerging as a powerful tool for health information transfer including making patient information portable. Such technologies can be more fully utilized through electronic patient information such as EMRs and EHRs. Electronic records will work best, however, if there are standards in place for their use and interoperability.

2.5 Interoperability of patient data

The purpose of collecting and storing patient information is to make it available for decision-making at a point of care or for analysis and action for management and policy. It is important to realize that most individual patients have more than one point of care. They may have a primary general care provider and specialist care providers. They may move from one location to another, including from country to country. It is essential that their individual patient information be available at all points of care and all sites for analysis. In order for this to work, there must be standards for representing the data and for communication. Distributed health data networks have been proposed to improve the ability to collect and analyse data across institutions leading to improved effectiveness, safety, and quality of care (26).

In the health field, there are several common nomenclatures that have been developed and are maintained by various organizations. The International Health Standards Development Organisation developed the Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT)⁵, which comprises the SNOMED classification system with Clinical Terms (Read codes), developed by the College of American Pathologists and the United Kingdom's Department of Health, respectively. WHO maintains the International Classification of Diseases (ICD) (27) as well as the International Classifications of Functioning, Disability, and Health (ICF) (28) and International Classification of Health Interventions (ICHI).⁶

⁵ <http://www.ihtsdo.org/snomed-ct>

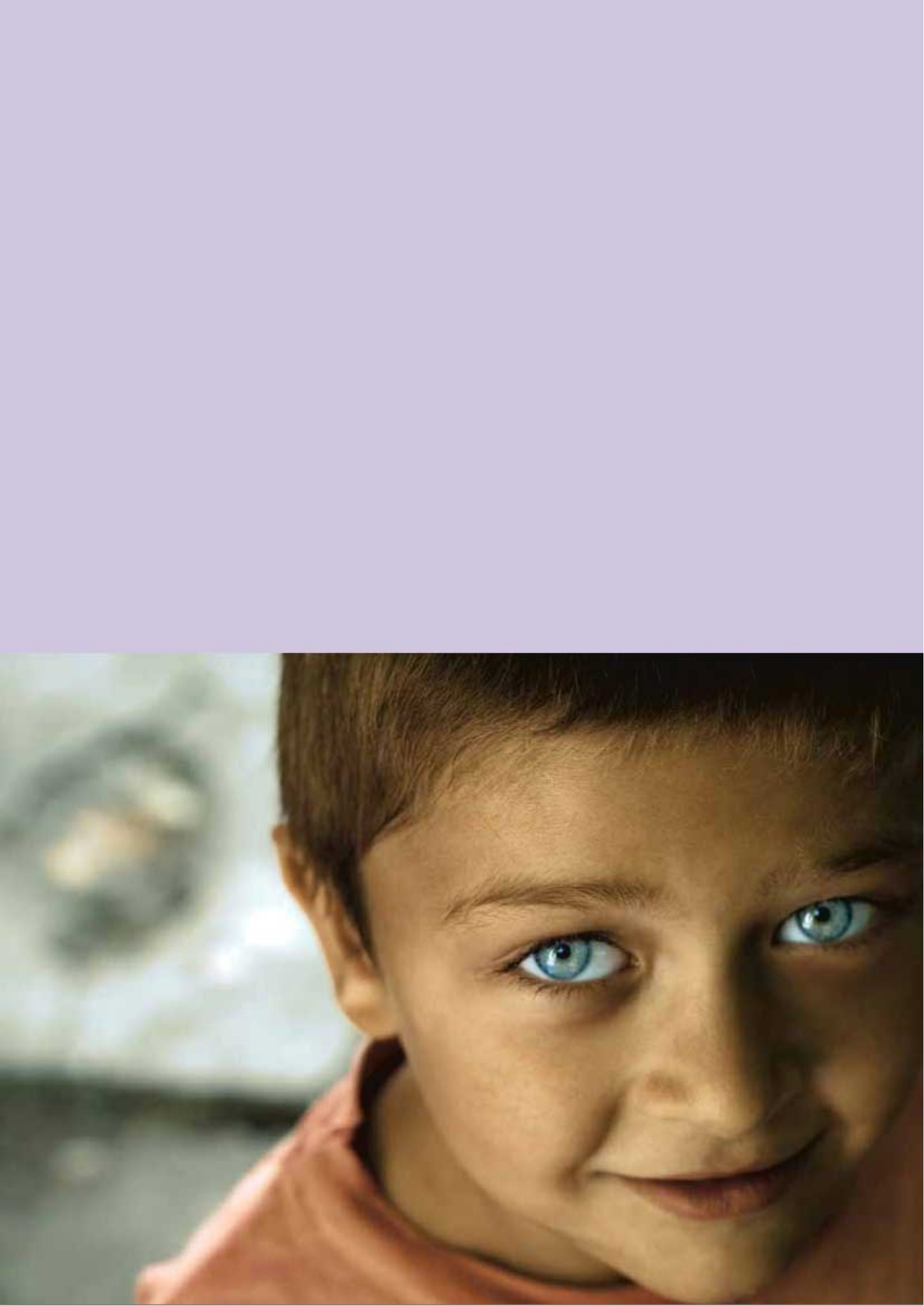
⁶ <http://www.who.int/classifications/ichi/>

2.6 Conclusions drawn from the literature

There are now compelling arguments for the adoption of information and communication technology in health care due to its potential for improving the efficiency of health care delivery and quality of care, particularly through interoperable data standards.

The beginning of such standardization is electronic patient records (EMRs and EHRs). The main advantages of these records relate to improved legibility and comprehensiveness of recording information, improved access to timely data by care providers and for access by multiple users (not geographically bound) and the ability to incorporate professional support tools such as guidelines and expert analysis. In addition, EHRs have the ability to use multimedia including images, sound, and video to provide comprehensive patient information.

Several core aspects of eHealth implementation are crucial. The first is the need to ensure that data are exchangeable. Interoperable data standards are fundamental requirements that are frequently overlooked, with the result that many sites are unable to share data thus limiting the flow of information. Interoperability depends on agreed standards enforced across all applications. Second, attention must be paid to data quality since this will impact the quality of decisions. Finally, health ICT systems require skilled personnel for their development and maintenance. Therefore training (e.g. computer literacy, program usage) and human resources development are critical components within systems, and must be addressed.



3

Analysis of survey results



3.1 Survey methodology

Results of the second global survey on eHealth are presented within the context of three classifications: adoption by WHO region, World Bank income group, and globally. For more details on this as well as the purpose of the survey, the design of the survey instrument, its implementation and limitations, please refer to Appendix 1.

3.2 Collection and use of patient information

Capturing and using individual patient information (in an EMR/EHR) is in some ways the last frontier of health information. Most countries have fairly well developed systems for capturing aggregate health data from clinics for use in disease surveillance and health status. However, it is more difficult to capture and use individual patient information electronically. Individual patient information is detailed and complex which means that computer software designed for this purpose must reflect its complexity. Capturing and using individual patient information electronically also requires installation of computer equipment at or close to the point of care. In addition to the cost of the computer hardware and software, EMR/EHR systems require substantial resources including electricity, a controlled environment, training, maintenance and support.

The survey contained a module on the management of patient information at the local, regional/district, and national levels. It included separate questions about aggregate patient information and individual patient information.

Levels of implementation

Although it is possible to define levels of transition from paper-based systems to computerized systems with a much finer level of detail, a simplified maturity model with three methods of data collection (levels of technological implementation) was used in the survey.

- Paper-based systems: Information is recorded on paper and data are transferred from paper for analysis or use.
- Computerized data: Data are entered into a computer (often from paper) from where they can be analysed and retrieved.
- Computerized data and electronic communication: This most advanced level combines the use of computerized data with the ability to electronically transmit it to multiple users in multiple locations.

Format use

Survey respondents were asked to estimate the use of a format on a five point scale starting at “none” indicating no use to “very high” meaning over 75%. Details of the measurement scale are found below.

None	no use
Low	below 25%
Medium	25 to 50%
High	50 to 75%
Very High	above 75%

These categories are sufficiently broad to offer a measure of accuracy while providing meaningful quantitative results from which conclusions can be drawn. All countries have a broad range and mix of adoption of technology: countries with low overall adoption still often have pockets of higher adoption; and countries with high overall adoption usually also have pockets of lower adoption. Considering these variations the expert respondents were asked to give an average for the country as a whole.

Survey analysis was performed according to a number of criteria including individual and aggregate patient information as well as by the three administrative levels of the health system including local, regional/district, and national.

In order to gain insight into the results, the global responses were also analysed by World Bank income group (see Appendix 1 for details of these groupings) and by WHO region. Tables 1 and 2 provide summary data of the trends identified in the transition from paper to digital records.

Table 1. Use of paper and electronic formats for individual patient data, by health system level and income group

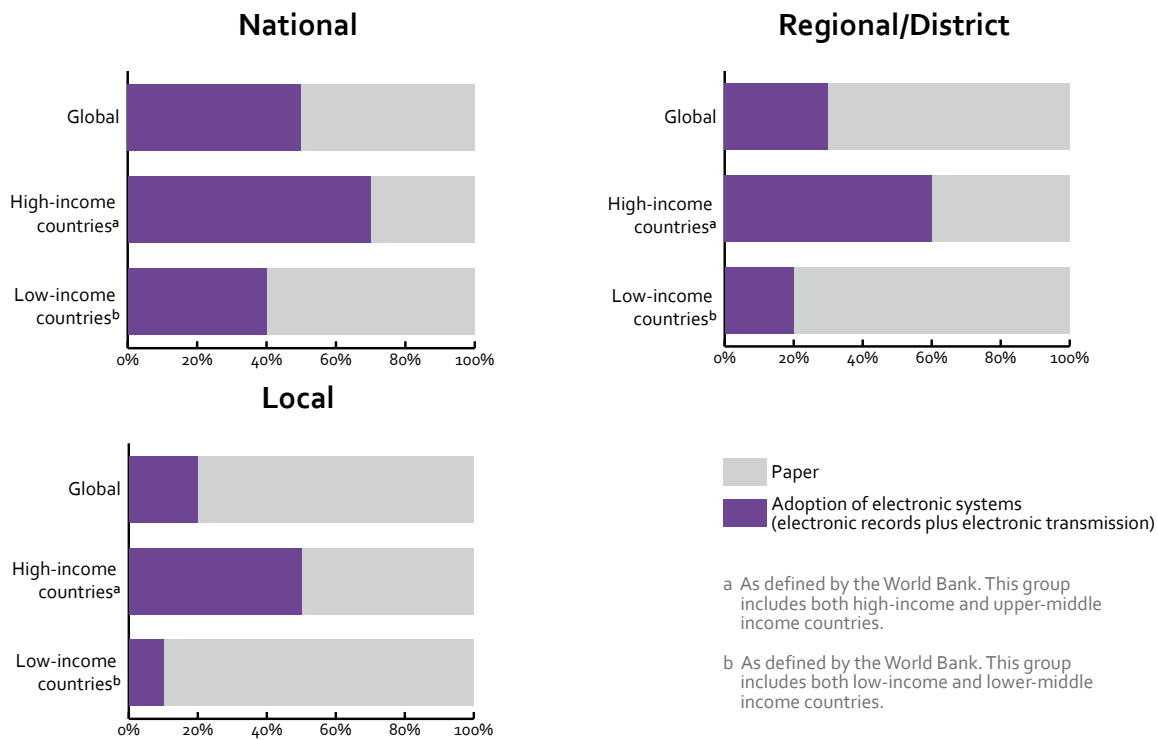
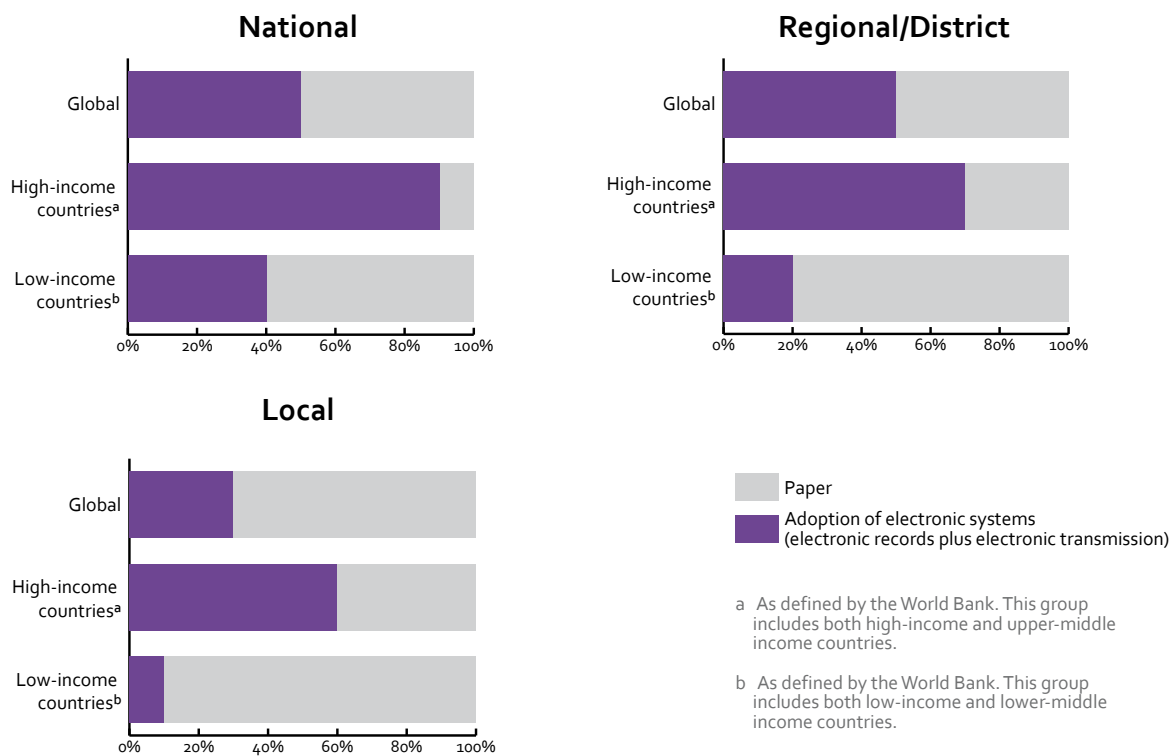


Table 2. Use of paper and electronic formats for aggregate patient data, by health system level and income group



3.3 Local health care facilities

Local health care facilities include clinics, hospitals, and community health sites and primary health care centres. These are the first points of care and encounters with patients and the 'front line' of the health information system. It is not only the source of patient data but also the location where the information can be put to immediate use to guide the diagnosis and care of patients to improve health.

Individual patient data

Individual patient information is collected and tagged with a patient identifier and can later be retrieved by that identifier. Each patient has their own record of encounters and it is often possible to view a longitudinal history of encounters for an individual patient. The advantages of this are that a personalized record of the patient's health status, diagnoses, treatments, and response to treatments is built over time. This allows the health-care professional to be well informed about the individual's history and to make better decisions about diagnosis, care, and treatment.

Key findings

- Most patient data are still collected on paper.
- Countries in higher income groups have higher adoption of EMR/EHR systems.
- Adoption of patient information systems is linked to country resources.

Figure 1. Individual patient data collected in local health care facilities, globally

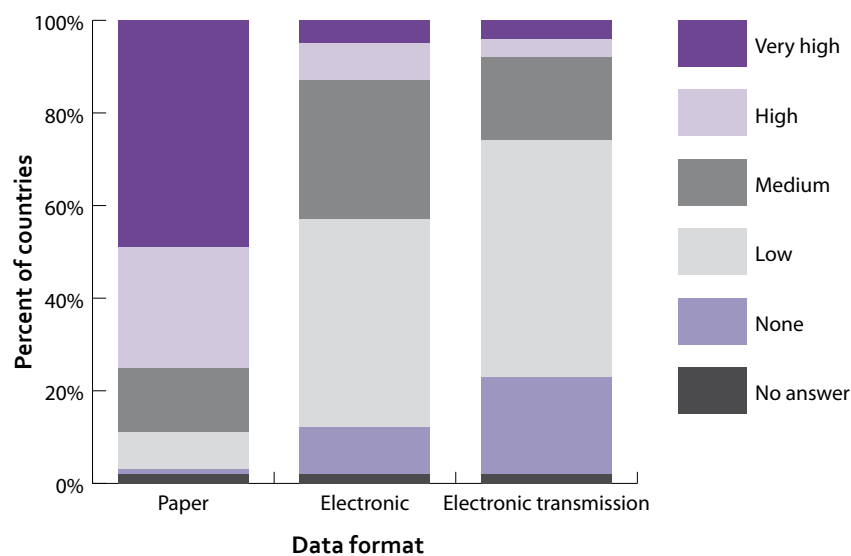
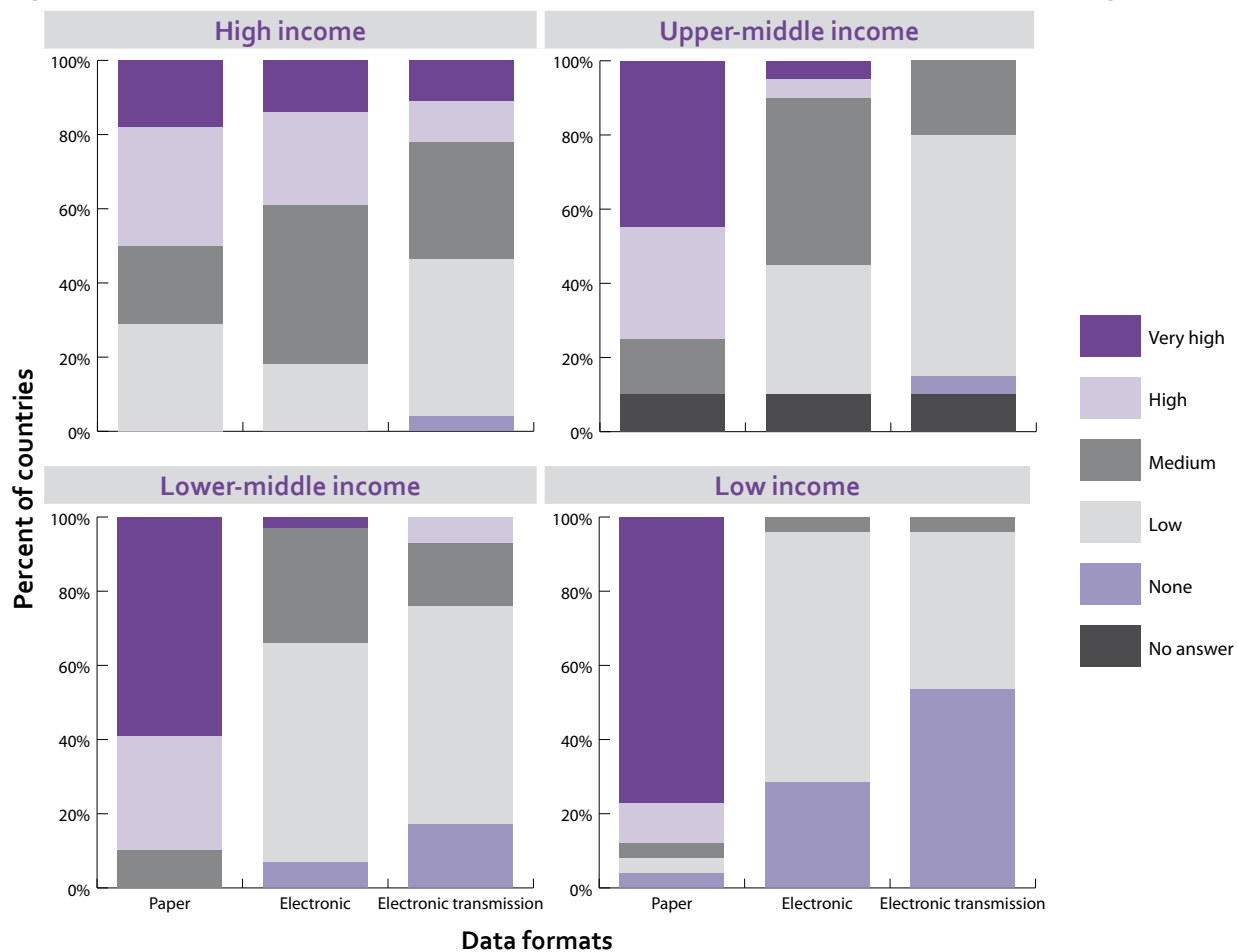


Figure 1 shows the global responses to the question about individual patient data. Each bar in Figure 1 represents one of the three modes of collecting and disseminating patient information: paper, electronic, and electronic transmission. Viewed in sequence, the differences in adoption of the three modalities can be seen. It is clear that the majority of patient information is still collected on paper (over 90% of countries reporting very high, high or medium adoption) with much lower levels of data collected in electronic format (45% reporting very high, high or medium adoption) and still lower levels being collected and communicated electronically (around 30% reporting very high, high or medium levels of adoption).

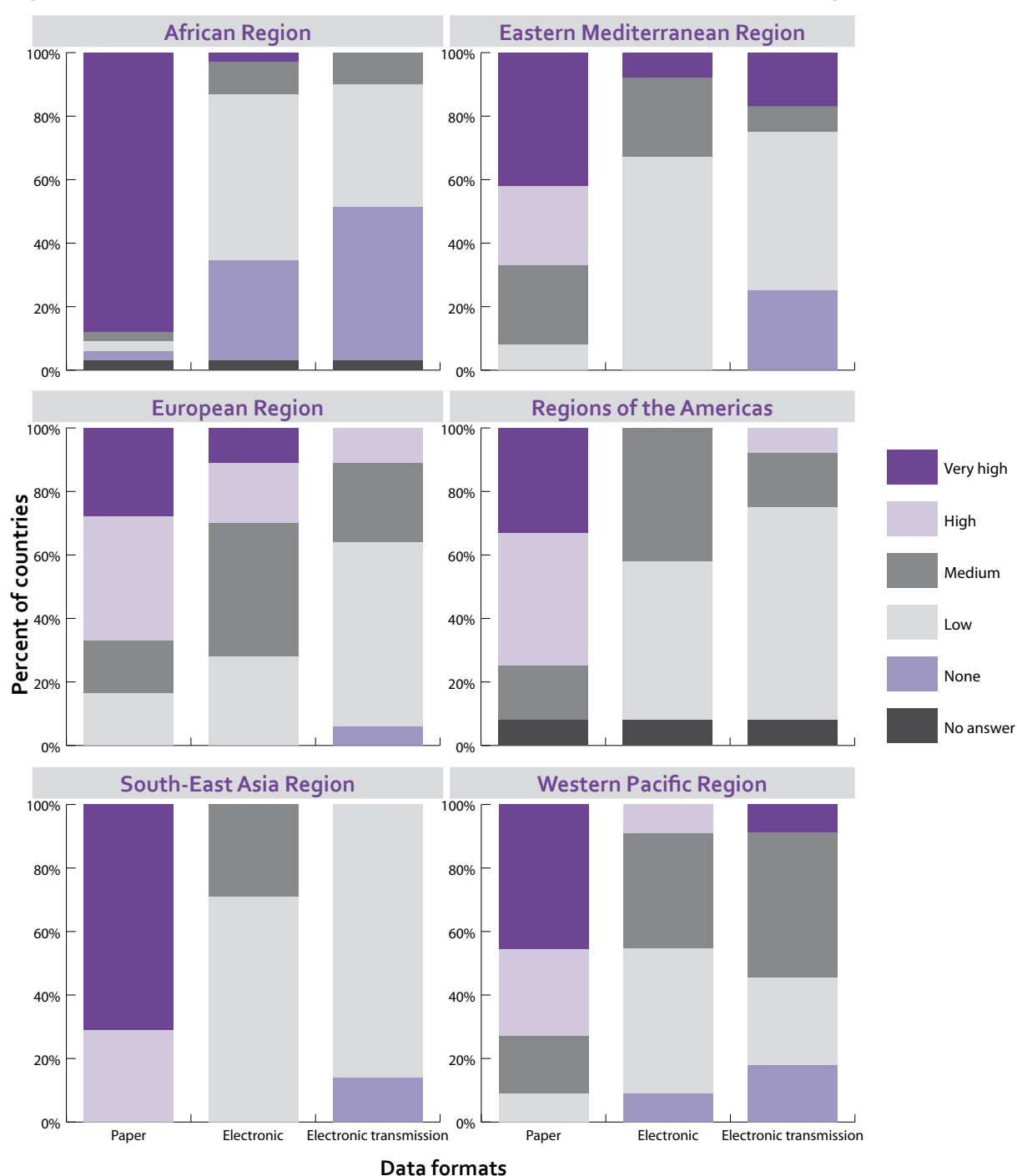
Figure 2. Individual patient data collected in local health care facilities, by World Bank income group



There appears to be a direct relationship between country income and the adoption of electronic patient information systems and communication of data. Figure 2 shows that high-income countries report “medium” to “very high” use of electronic information systems in over 50% in these categories for electronic communication of health data. In contrast, only a small percentage (4%) of low-income countries report “medium” adoption of electronic patient information systems and communication of health data and none report higher levels of adoption.

These patterns of adoption can be primarily explained by the fact that high-income countries have the clear advantage of greater available resources and access to trained professionals to implement electronic patient information systems at the local level.

Figure 3. Individual patient data collected in local health care facilities, by WHO region



When the same data are analysed by WHO region (Figure 3), it can be seen that all regions have high paper use, with the African Region and the South-East Asia Region reporting the highest levels. It is interesting that the Eastern Mediterranean Region, the Region of the Americas, and the Western Pacific Region show a higher adoption rate of electronic transmission of data than actual collection of patient information in electronic format. This may be due to the use of fax or scanned image technology where the communication is electronic but the original is in paper format. It could also be the case that data are transferred offline using compact discs (CDs) or cassette tapes between data centres from the health care centre to the districts or central agency.

Aggregate patient data

The data collected from individuals can be aggregated to give counts of various diseases, health status, diagnoses, and treatments. In basic health information systems, data may be aggregated directly at the time and point of care using tally sheets or totalled from registers. If there is an electronic system in place to collect such information, aggregation can be done automatically by a computer counting the incidents of interest over a given time period – this might provide early evidence of emerging (or re-emerging) diseases.

Key findings

- Use of electronic formats is higher for aggregated data than individual data.
- There is a relationship between country income and the use of electronic formats.
- High-income countries have transitioned to the point where there is a greater use of electronic formats than paper-based records.

Figure 4. Aggregate patient data collected in local health care facilities, globally

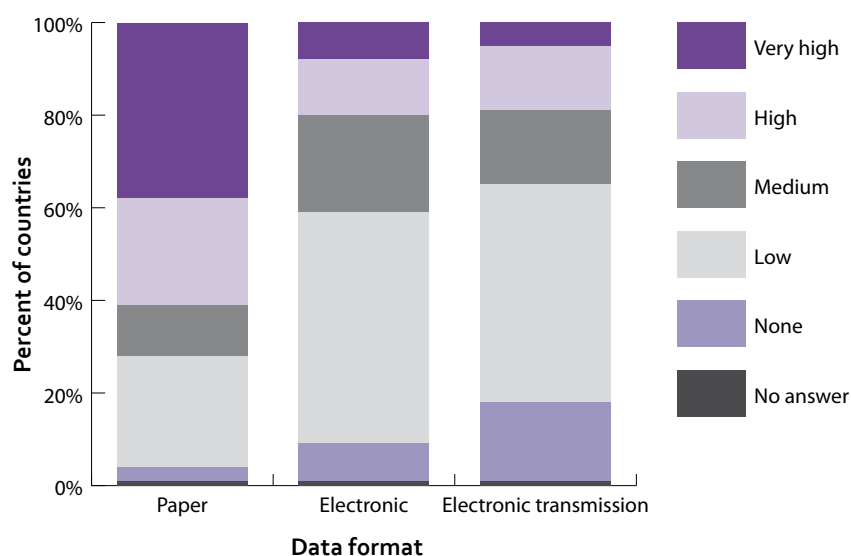
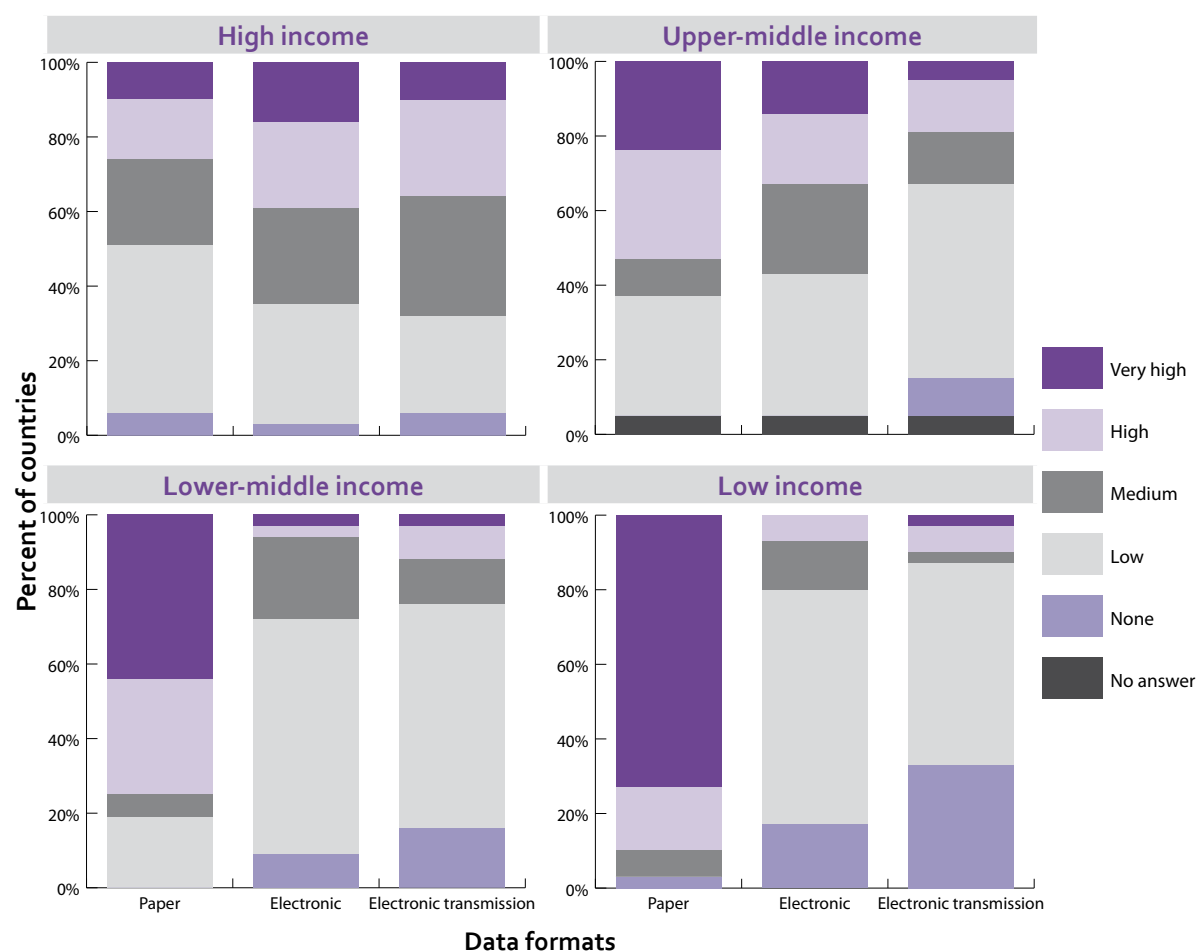


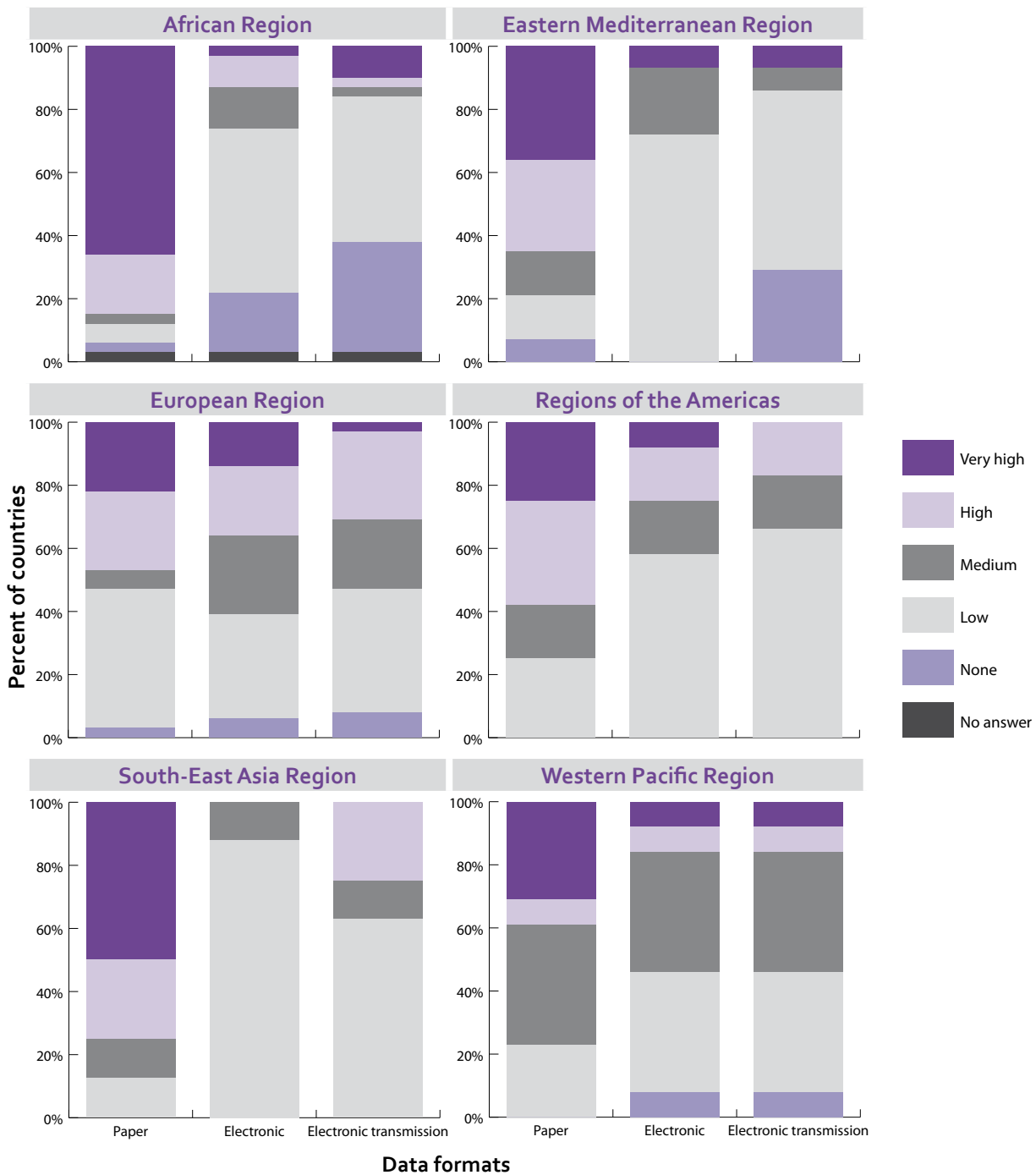
Figure 4 shows there is still a large proportion of countries worldwide using paper to record health data. Results show that use of electronic formats for aggregate patient data is higher than for individual patient data, except at local levels where it appears many facilities are collecting and using their aggregate data on paper. While this may be feasible for local use, paper-based reporting at higher levels of the health system is more cumbersome (labour-intensive) and prone to error.

Figure 5. Aggregate patient data collected in local health care facilities, by World Bank income group



When countries are grouped by World Bank income group, the high- and upper-middle income groups contain a significant number of countries (but still a minority) using electronic formats (Figure 5). Even this limited usage drops to a very small number of lower-middle and low-income countries. These developing countries are handicapped by a lack of resources (financial, technical, and human) which makes implementing systems at the local facility level very difficult.

Figure 6. Aggregate patient data collected in local health care facilities, by WHO region



It is interesting that countries of the South-East Asia and Western Pacific Regions have made greater use of electronic communications than actual electronic collection formats (see Figure 6). As already noted, this may be explained by countries using digital communication formats such as fax to send paper-based reports.

3.4 Regional/District offices

Regional or district offices are a crucial management link for most health care systems; these are the offices which directly manage local health facilities. Often regional or district offices will have a number of local care facilities to manage. It is at this level that local facilities are closely monitored and improvements in the delivery of services suggested. Timely, accurate, and representative data from local facilities is crucial to this work.

Regional or district offices are often involved in immediate short-term operational planning for the facilities and this function also requires access to timely information. These offices can benefit from electronic information formats and communication. Often there is some significant distance between the regional or district office and local care facilities, which can make the use of electronic communication formats particularly useful.

Individual patient data

Key findings

- A limited number of countries reported widespread use of electronic formats and communications.
- Industrialized countries have a small but significant use of electronic formats and electronic communication.

Figure 7. Individual patient data collected in regional offices, globally

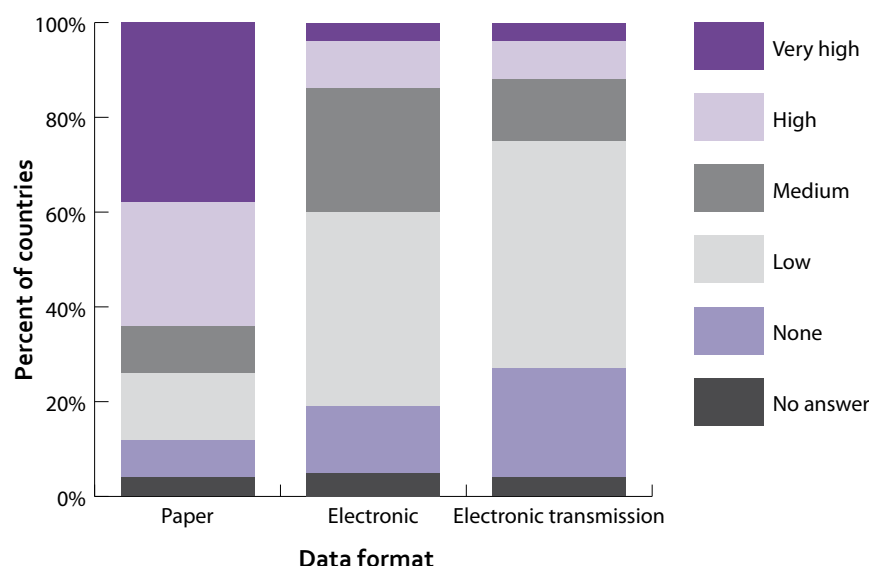
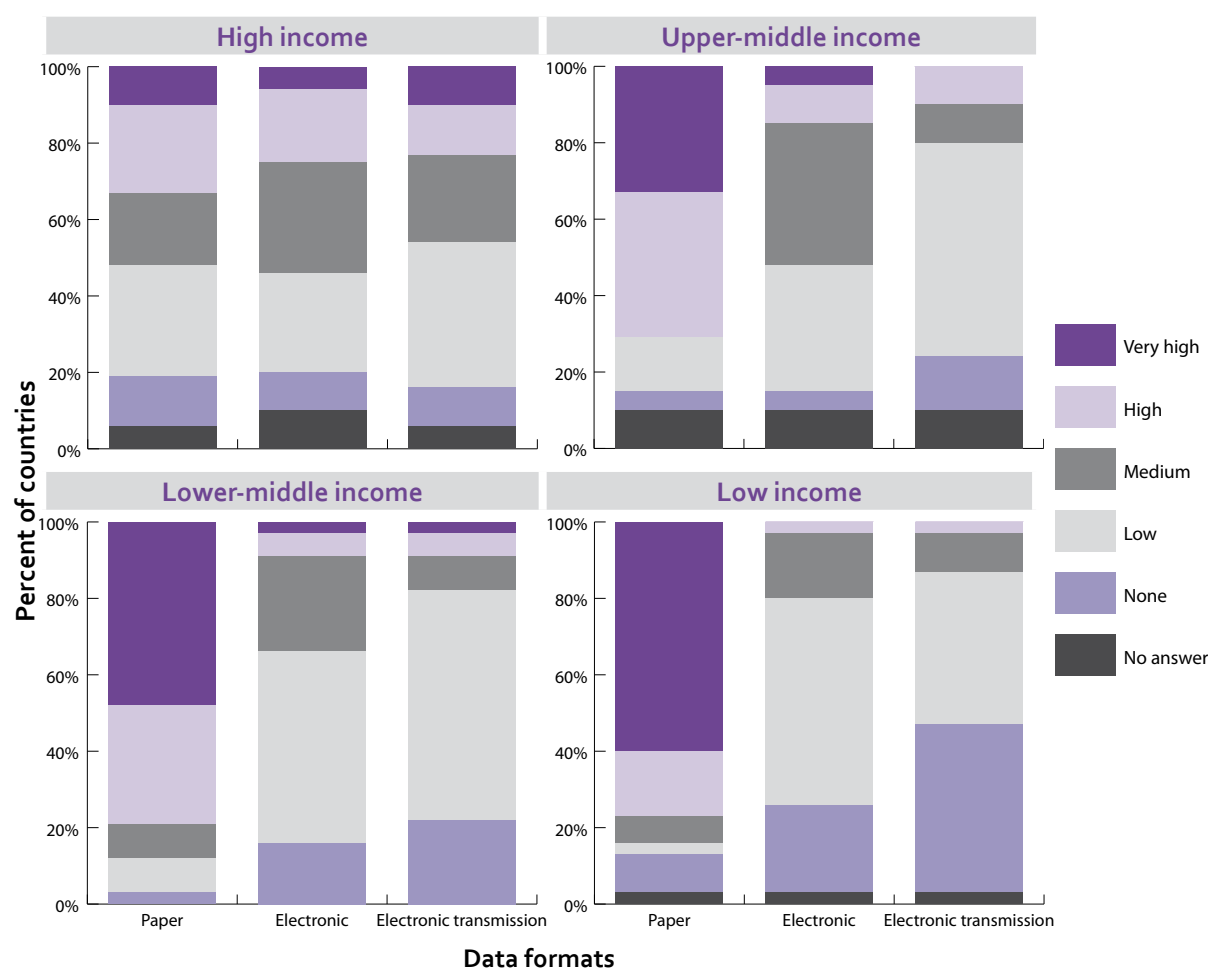


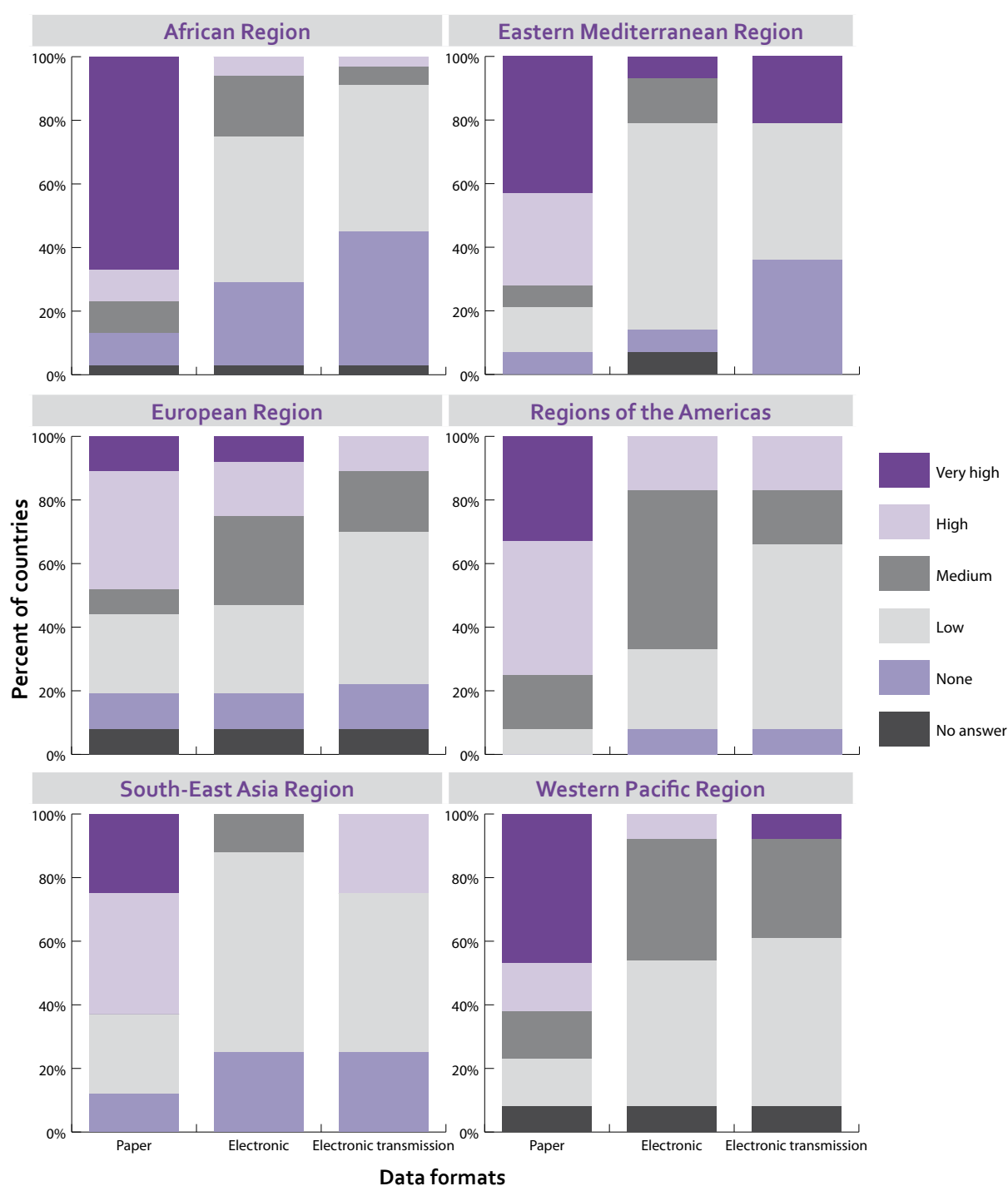
Figure 7 shows that most responding countries reported that they continue to use paper-based methods of collecting patient information at the regional level with 38% and 26% reporting “very high” and “high” use, respectively. Given this, 67% of responding countries reported “low” to “medium” use of electronic systems.

Figure 8. Individual patient data collected in regional offices, by World Bank income group



Responses by World Bank income group are shown in Figure 8. The trend is similar to that found at the local level: mostly paper-based data recording. Low and lower-middle income countries report both “very high” and “high” use of paper-based systems accounting for just under 80% of responding countries. While upper-middle income countries report similar levels of the use of paper as the two lower-income country groups, countries in this group have made greater strides towards digitization: approximately 38% reported a high level of electronic records and their transmission.

Figure 9. Individual patient data collected in regional offices, by WHO region



Approximately 70% of responding countries from the African Region reported “very high” use of paper-based systems followed by the Western Pacific (46%) and Eastern Mediterranean (43%) Regions (Figure 9). The pattern of using paper-based systems is relatively consistent across all regions, as is the use of electronic patient information and communications systems, which is largely rated as “none” or “low”. The “low” deployment of electronic transmission of patient information ranged from 42% (African Region) to 58% (Region of the Americas). The general trend of countries using mainly paper-based systems is evident.

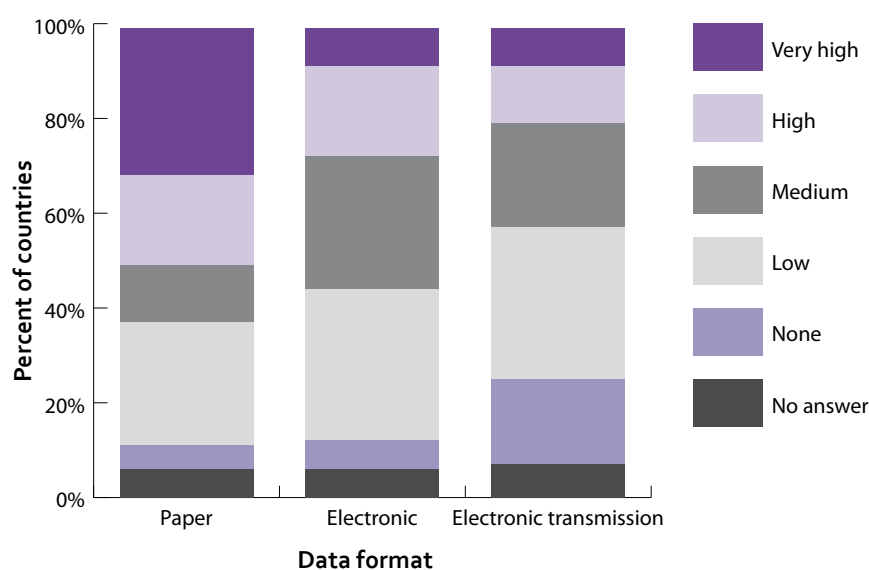
Aggregate patient data

Aggregate patient data provide the core data on which regions or districts depend to properly perform their critical management functions, which includes allocating human resources and materials and supplies for the operation of local facilities. Monitoring and evaluation activities are integral to that management. Information on health status such as numbers of cases of illness, injury, or pregnancy give these offices important feedback on the effectiveness of their programmes, which in turn can be shared with national and international donors.

Key findings

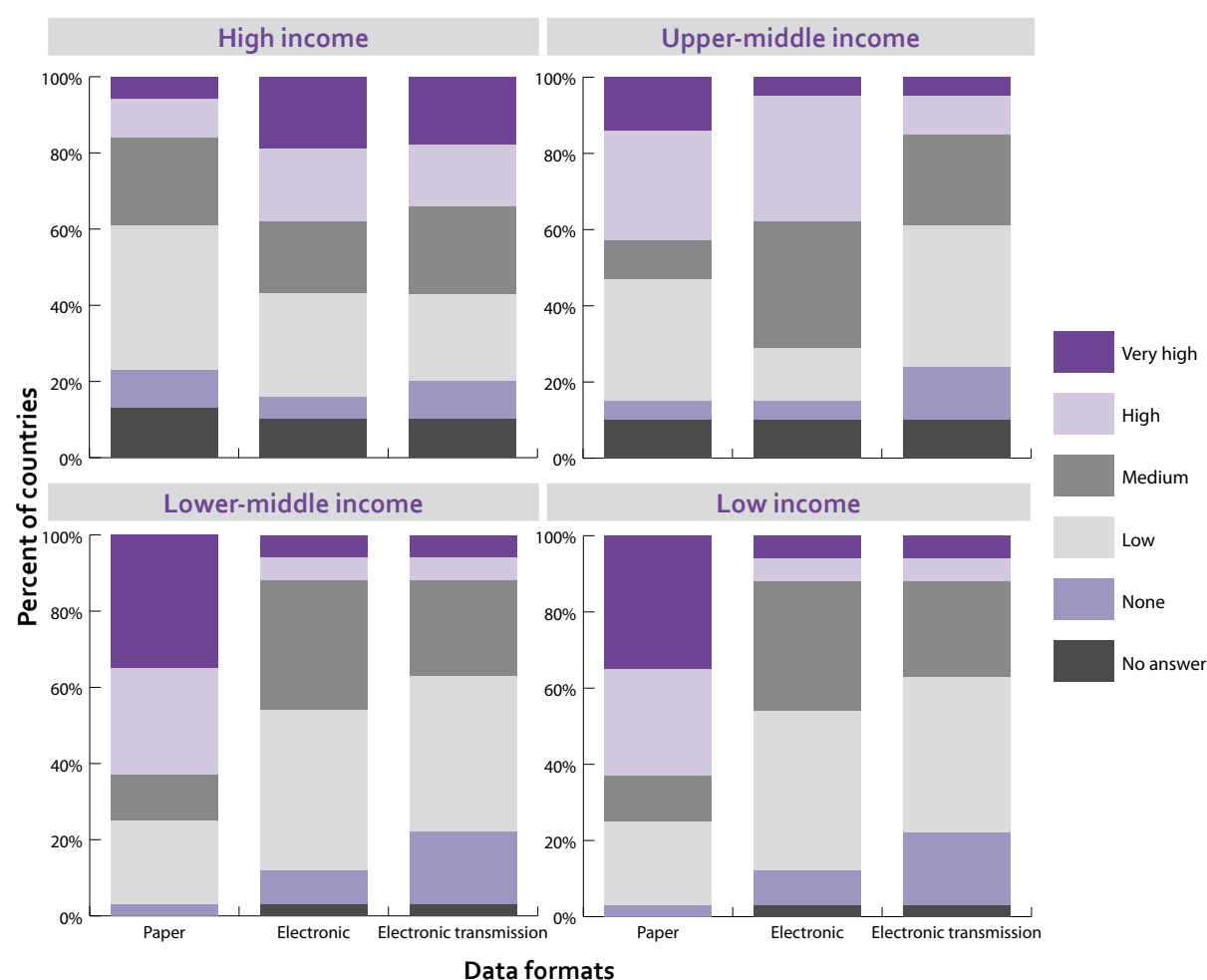
- Paper-based systems continue to be the most widespread of all formats used in health systems at the regional/district level.
- Low-income countries in particular have high use of paper-based systems and low use of electronic formats.

Figure 10. Aggregate patient data collected in regional offices, globally



Globally, there is still a high use of paper-based systems accounting for 31% of responding countries ranking its deployment level as “very high”. There is also generally “low” deployment of electronic patient data and electronic communication systems with these systems showing “none” or “low” deployment (approximately 37% and 48%, respectively; Figure 10).

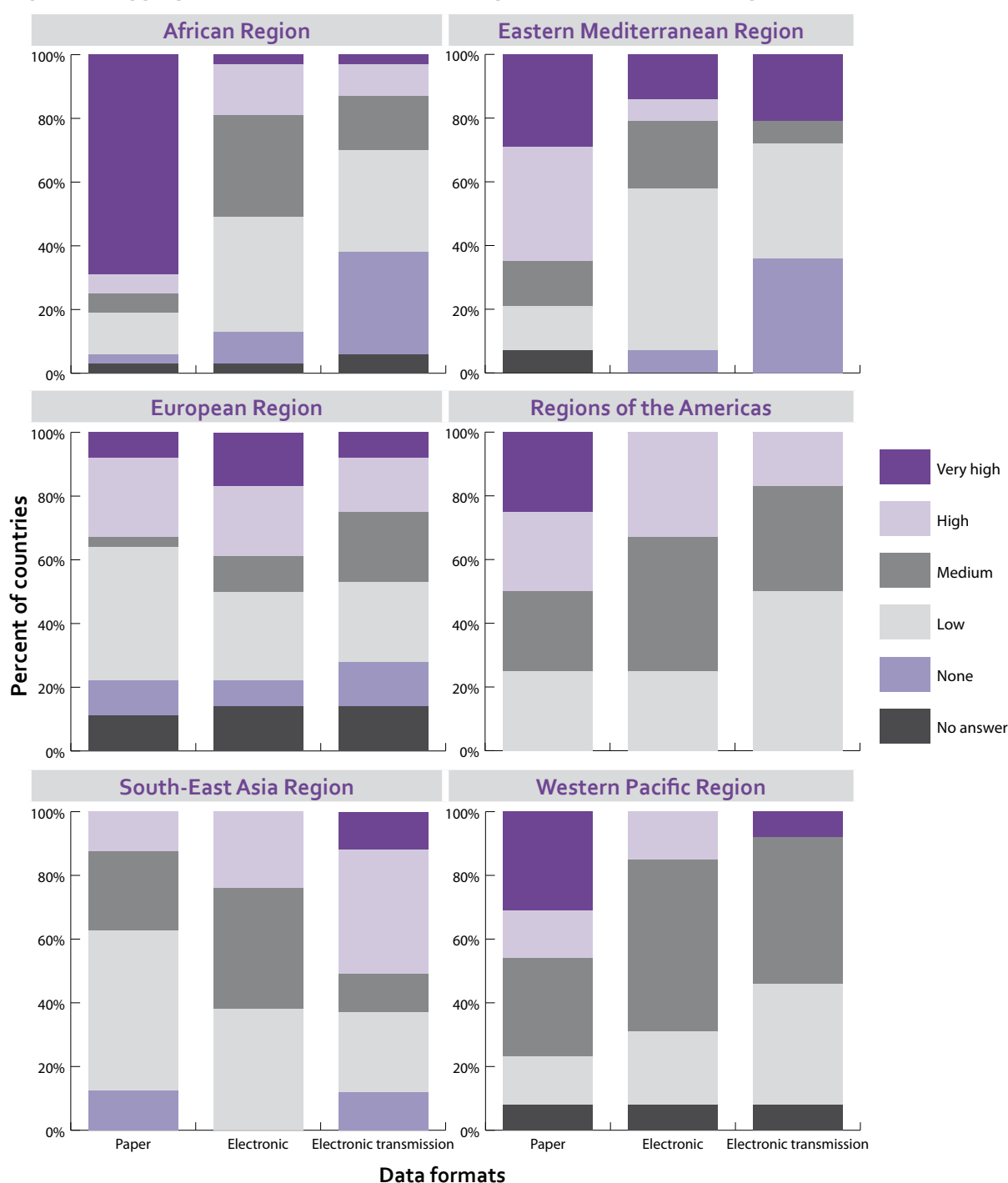
Figure 11. Aggregate patient data collected in regional offices, by World Bank income group



The deployment trend of paper-based systems compared to electronic formats across all World Bank income groups is clear: the use of paper-based systems is higher in countries of the lower-middle and low-income groups than those in the high- and middle-income groups; and the opposite is true for electronic formats and electronic communications (Figure 11).

It is interesting to note that there is at least a “low” to “medium” level of deployment of aggregate electronic patient information and communication systems in lower-income countries. This could be due to the national health systems used in many low-income countries, which are usually set up to facilitate the collection of aggregate data. High-income countries have a more diverse system for delivering care including an active private sector where it is more difficult to collect data.

Figure 12. Aggregate patient data collected in regional offices, by WHO region



Countries of the WHO African, Eastern Mediterranean, and Western Pacific Regions show a “high” level of paper use and “low” use of electronic systems (Figure 12). The European Region’s “high” deployment of both paper-based and electronic patient information systems is at 25% and 22%, respectively. The South-East Asia Region shows a higher use of electronic transmission of patient information than use of electronic health records (50% and 22%, respectively), but overall noting of data is low. Thus, it appears that where data are recorded, they are being electronically transmitted roughly half the time. Again the data show that the European Region and Region of the Americas are more advanced in the transition to digital formats, and that the African Region is likely to have the most significant challenges digitizing their records in the future.

3.5 National level

At the national level, individual patient data are most useful for operational research, planning, and policy. Longitudinal records of the history of individual patients can be useful in tracking the course of diseases and responses to treatment, which, when put into action, benefits individual patients.

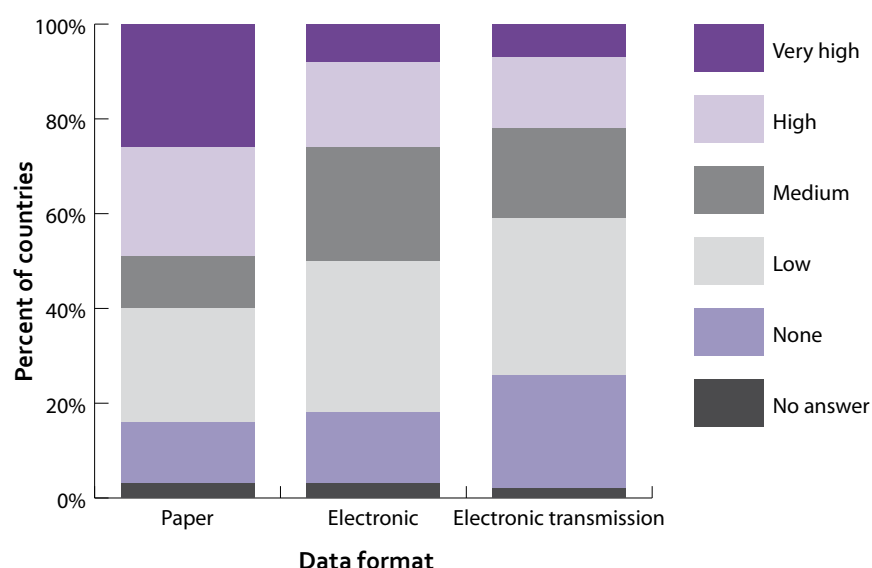
Individual patient information

While the use of paper is still very high for managing individual patient information at the national level, there are instances where countries have started to collect individual patient information to build longitudinal medical records. For example, the United Kingdom has adopted a national system while several European countries such as Denmark, France, and Germany make extensive use of electronic health records. Across the Atlantic, the United States has put in place significant financial incentives for health services to adopt electronic patient records.

Key findings

- The use of paper-based systems continues to be high for individual patient data at the national level.
- Countries in the high and upper-middle income groups tend to have higher adoption of electronic patient information systems.

Figure 13. Individual patient data collected at the national level, globally



Globally, the use of paper-based systems remains high for the collection of individual patient information with half of the participating countries ranking their use as either “high” or “very high” (Figure 13). While the use of electronic systems is low, it is higher than the use of such systems at local and regional/district levels.

The trend seen globally is the same when viewed by World Bank income group. Fifty per cent of low-income countries ranked the use of paper-based systems as “very high” compared to 6% in high-income countries (Figure 14). In addition, 20% of low-income countries marked “none” which is likely to indicate that some countries do not use electronic patient information systems for individual patients at the national level. Around 40% of high-income countries reported “high” or “very high” use of electronic formats and transmission with around 60% reporting “medium” or higher use.

Figure 14. Individual patient data collected at the national level, by World Bank income group

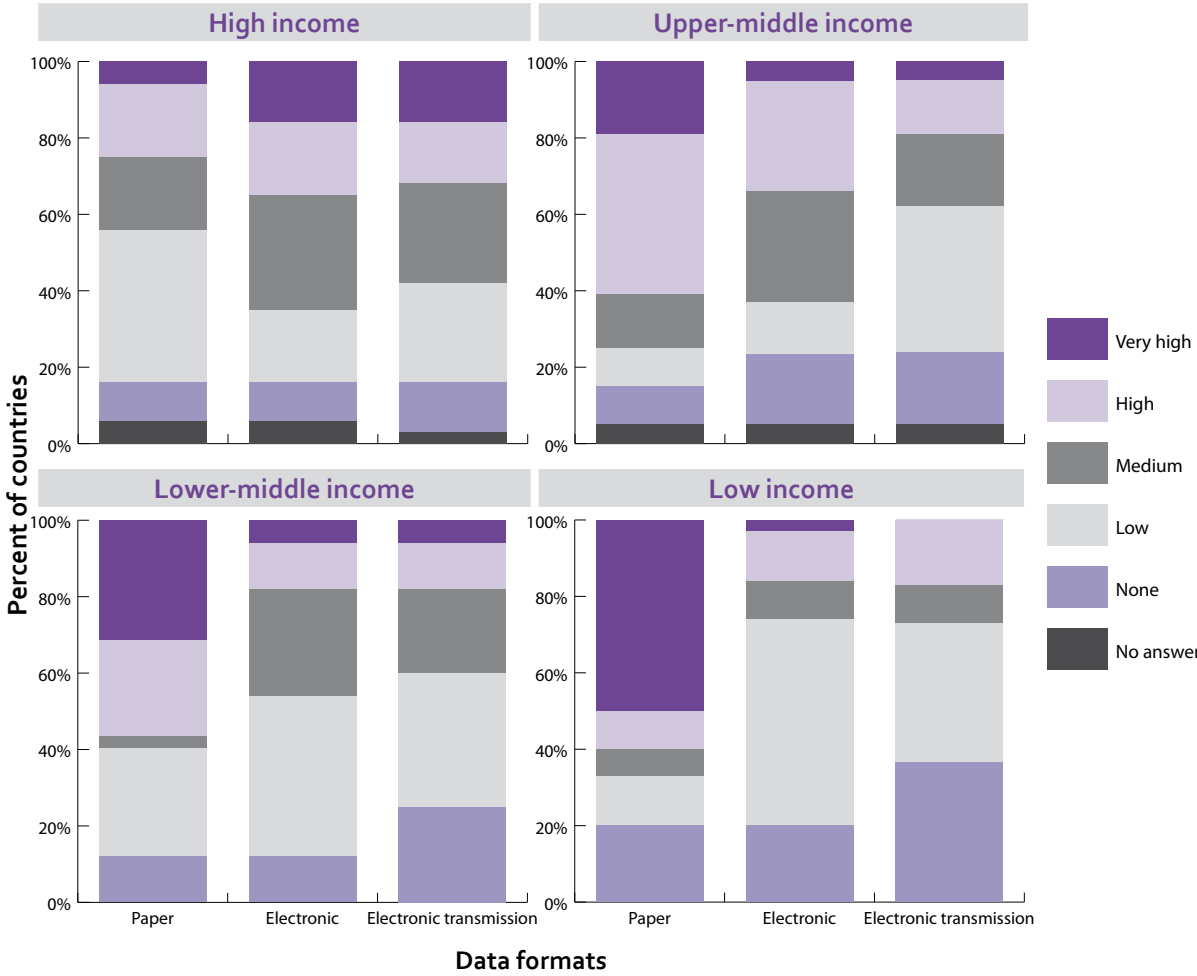
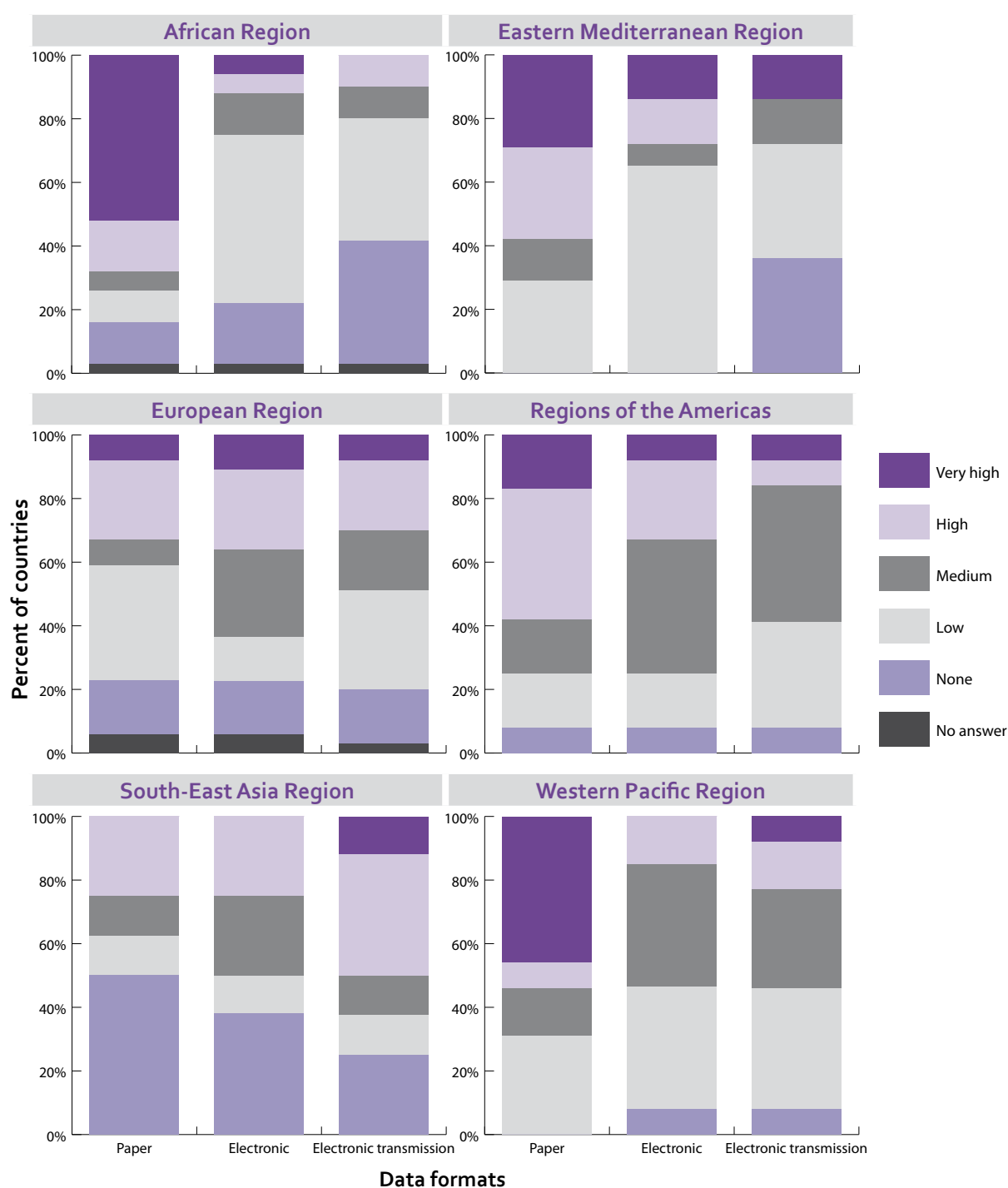


Figure 15. Individual patient data collected at the national level, by WHO region



The WHO regional differences are similar to the trends seen at the health facilities and regional/district levels. The African Region reported the highest use of paper-based systems at 68% (Figure 15) and 39% reported low use of electronic and electronic communication formats (52% and 39%, respectively). Approximately one quarter of countries in the European Region reported “high” use of paper-based systems, which was roughly equivalent to the number of countries reporting “high” use of electronic formats for health records.

Aggregate patient data

Aggregate patient data is useful at the national level for planning, policy formulation, programme management, monitoring and evaluation, and disease surveillance. By understanding disease status, trends, patterns and response to interventions, resources can be better allocated.

Key findings

- Globally, approximately one third of responding countries collect aggregate data in electronic formats and one third transmit it electronically at the national level indicating fairly widespread adoption of electronic systems.
- High-income countries have clearly moved to electronic formats with a majority reporting “high” to “very high” use of electronic data collection and transmission at the national level.
- Countries of the South-East Asia, Western Pacific, and Eastern Mediterranean Regions show a higher use of electronic communication modalities than electronic data collection. This could be due to widespread use of mobile telephone communications technology.

Figure 16. Aggregate patient data collected at the national level, globally

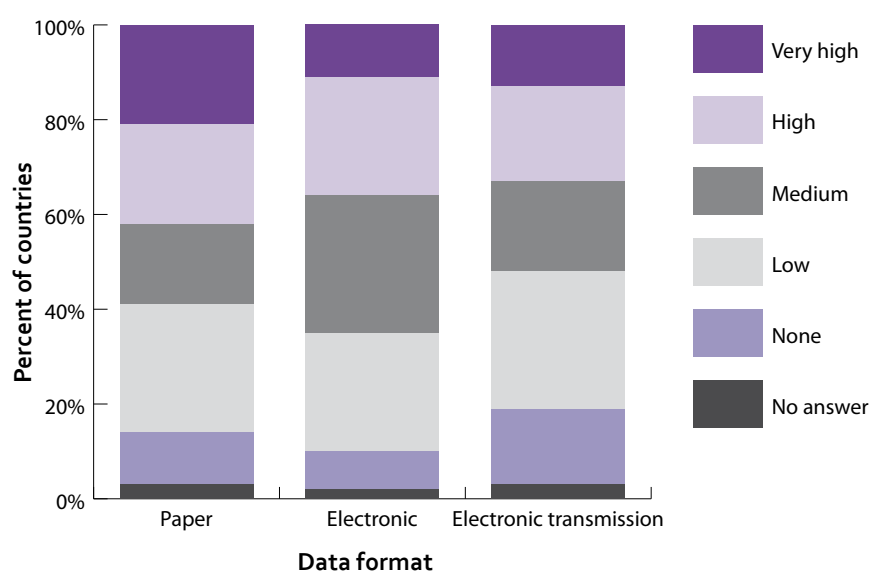
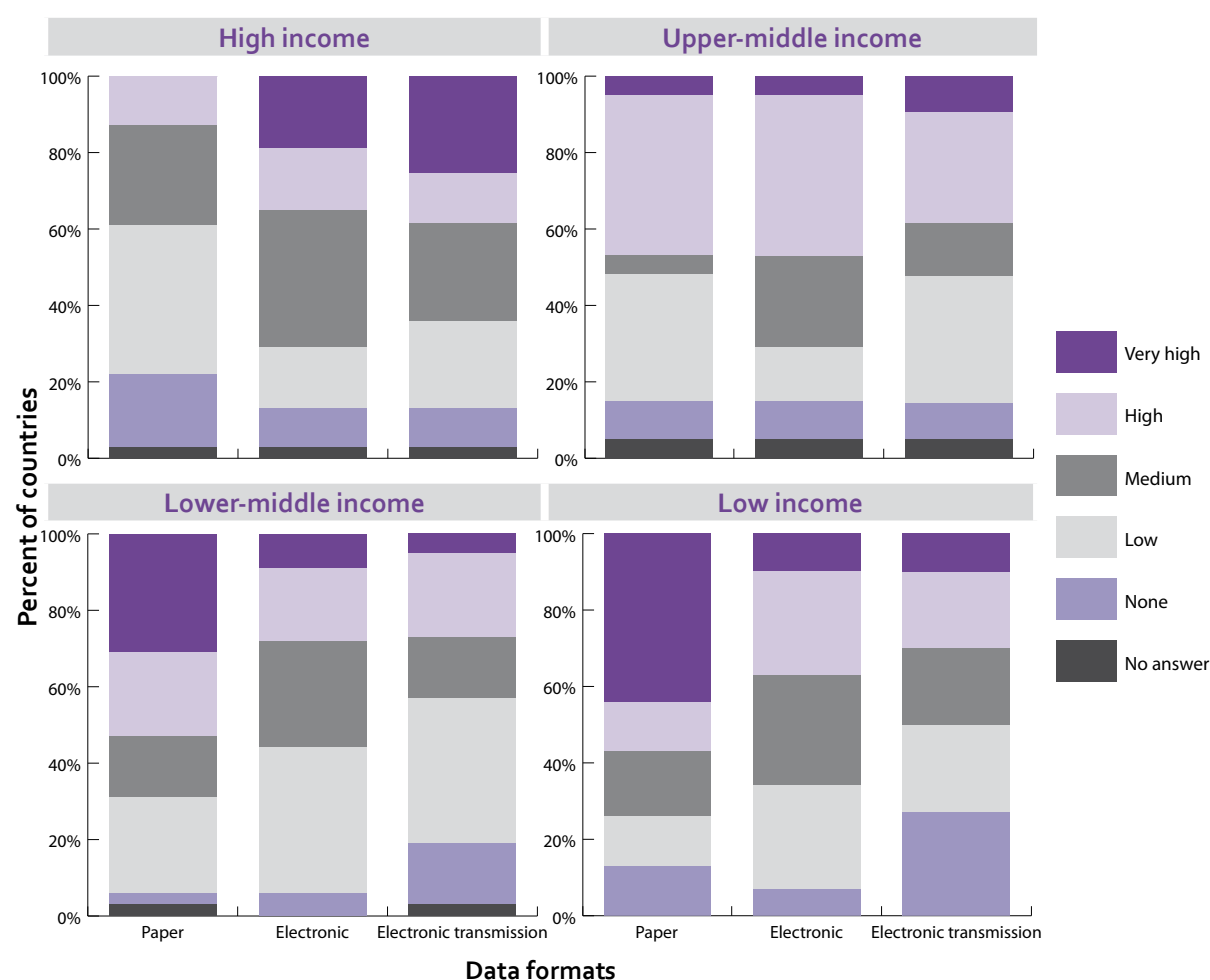


Figure 16 shows that one third of countries reported “high” to “very high” use of electronic records and electronic transmission of data, respectively, at the global level. This is contrasted with 42% of countries reporting these answers for use of paper-based systems. The gap between those using paper and electronic systems is much smaller than seen at local and regional levels, which indicates that use of electronic systems for data collection and dissemination is growing.

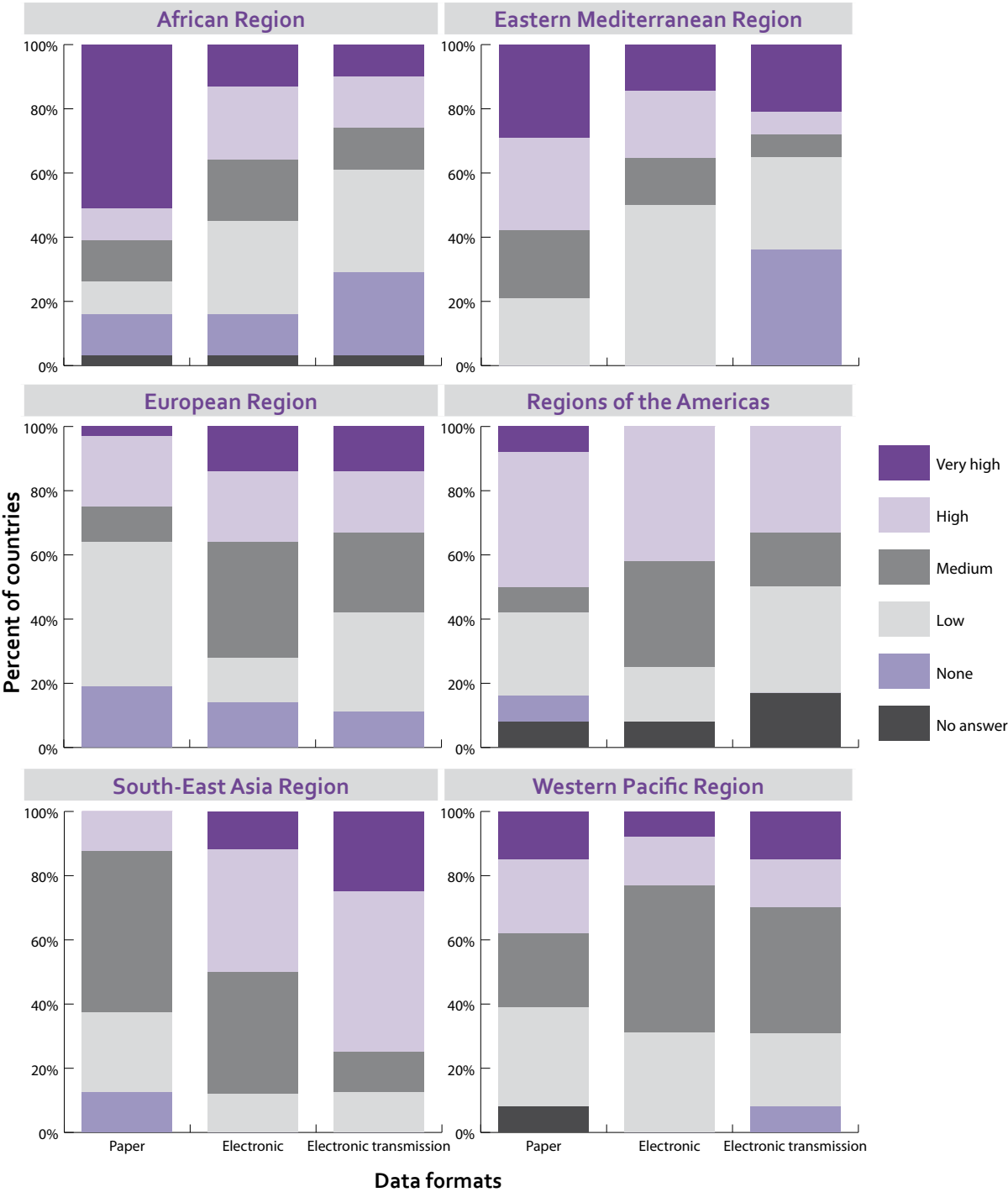
Figure 17. Aggregate patient data collected at the national level, by World Bank income group



The trend of increased deployment of electronic systems seen globally does not appear to apply to low-income countries, however: when country responses are reviewed by World Bank income group, both lower-middle and low-income countries continue to see “high” and “very high” use of paper-based systems (Figure 17). Close to 60% of countries in the low-income group reported that paper-based system use is “high” or “very high” and this drops to only 10% of the high-income countries reporting “high” use of paper-based systems.

Figure 18 shows the results by WHO region. The European Region reported the lowest level of deployment of paper-based systems and reported extensive use of electronic systems for data storage and transmission. The Regions of the Americas and South-East Asia also reported high rates.

Figure 18. Aggregate patient data collected at the national level, by WHO region



3.6 mHealth and patient information

The second global survey on eHealth also covered the use of mobile technologies for health. It defined mHealth as

an emerging term for medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices. mHealth applications include the use of mobile devices in collecting community and clinical health data, delivery of health care information to practitioners, researchers, and patients, real-time monitoring of patient vital signs, and direct provision of care.

The results show that most countries are conducting at least one mHealth initiative, indicating that they have been quick to realize the potential of this approach. Some mHealth initiatives which have been adopted at higher rates than others are health call centres and emergency call services. In addition, mobile telemedicine shows a high proportion of informal and pilot implementations. This reflects countries exploring how best to use this technology for the health of their populations. Other areas which have a relatively high adoption are patient reminders, appointment reminders, access to information, and community mobilization.

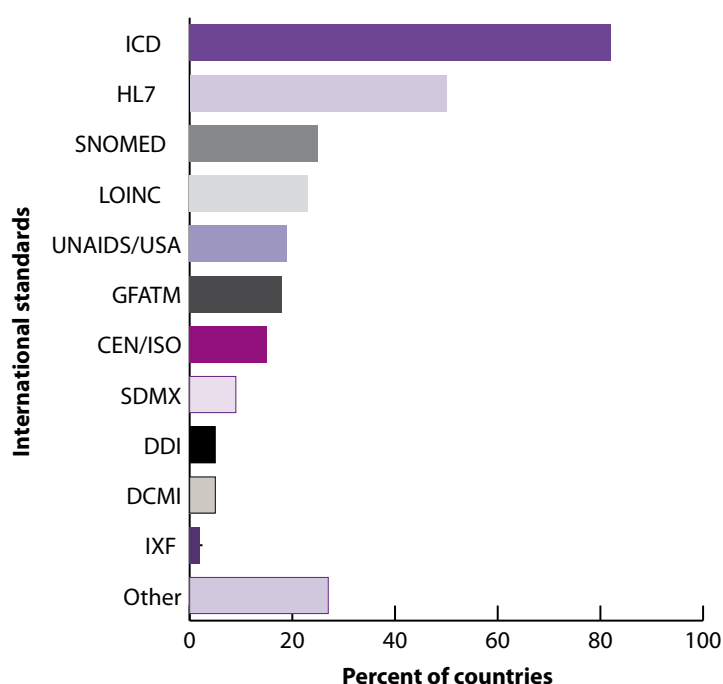
For further information, see *mHealth: new horizons for health through mobile technologies*, volume 3 of the Global Observatory for eHealth series (25).

3.7 International standards for eHealth

The adoption and use of standards can reflect the level of ICT development of a country and for this reason the survey explored this area. Electronic information systems rely on standards; in order to share and aggregate data, countries utilizing such systems need to collect data using standard definitions and formats. In order to exchange health data, systems must include syntax and semantic content that is clear and unambiguous to both sender and receiver. Due to the broad scope of health information and multiple (and often imprecise) terminologies in common use, this can pose a significant challenge.

Defining standards is a complex and labour intensive task. Fortunately, many international organizations have taken up the work of developing and maintaining standards. This gives countries access to well researched and defined standards that they can adopt and modify, if necessary, for their own use. Figure 19 shows the uptake of international standards for eHealth across responding countries.

Figure 19. Responding countries' adoption of selected international standards



The categories of standards in current use include the following.

- International guidelines assist organizations to adopt standards by describing how they can be used.
- Metadata standards are a common way of describing the content of the standards themselves.
- Messaging standards describe protocols to communicate data.
- Medical record standards specify the structure, content, and organization of individual patient medical records.
- Vocabulary standards define the terms used to describe health conditions and events.

International guidelines documents

A number of international organizations have developed guidelines documents which help countries adopt standards. Overall, these documents are reasonably popular among responding countries, which may well be due to their clear utility and ease of implementation. Examples are discussed below.

Global Fund to Fight AIDS, Tuberculosis and Malaria – the M&E Toolkit

The Monitoring and Evaluation Toolkit (29) provides a rich source of information, training and tools to improve monitoring and evaluation of health services. It provides a framework which presents a selection of standard indicators for acquired immunodeficiency syndrome (AIDS), tuberculosis and malaria and provides a reference to a range of M&E guidelines and tools on specific programme areas, which countries can use in developing indicators for their health information systems.

Eighteen per cent of the responding countries report using this toolkit to strengthen their health systems.

Confidentiality and security guidelines developed by UNAIDS/USG

Protecting the privacy and security of health information should be a high priority for all countries. However, the subject is complex and providing necessary access as well as confidentiality can be difficult in practice. That is why the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United States Government have provided a set of guidelines for the confidentiality and security of health information (30).

Nineteen per cent of responding countries have adopted these guidelines.

Metadata standards

Countries tend to be fairly advanced in the planning for information systems before they see the need for and adopt metadata standards. Ideally, countries should plan on using metadata standards as a first step. Unfortunately the importance of metadata is usually only understood after a country becomes involved with planning and information systems. Further complicating use of metadata standards is the lack of communication that is often in evidence between the professionals who develop digital information systems and those who develop the standards, which can hinder interoperability. Examples of metadata standards are discussed below.

Dublin Core Metadata Initiative (DCMI)

The Dublin Core Metadata Initiative⁷ is an organization engaged in the development of interoperable metadata standards, architecture, and modelling. Metadata is information that describes the source, characteristics, and environment of data. The purpose of defining metadata is to improve interoperability of data through standardization, that is, giving the collector and receiver of information as much information as possible on the context of the data so that the receiver will attach the same meaning to the data as the original collector.

Only 5% of countries responding to the survey use the DCMI model methodology. This low uptake could represent a lack of knowledge of the standard or difficulty in implementation.

The Data Documentation Initiative (DDI)

The Data Documentation Initiative⁸ is a metadata specification for the social sciences to promote data interoperability and integration, using Extensible Markup Language (XML) to express the data. It takes a life-cycle approach to data; from collection, analysis, publication, and management, data can be reprocessed at later stages of their life-cycle. This creates an iterative, circular process with respect to data usage.

Only 5% of responding countries report using this standard for their data. Its low level of adoption could be that the standard is not well known or is not considered appropriate for use in the health sector.

Statistical Data and Metadata eXchange (SDMX)

SDMX is an initiative for standards for statistical data and metadata exchange. The SDMX sponsoring institutions are the Bank for International Settlements, the European Central Bank, Eurostat (the

⁷ <http://www.dublincore.org>

⁸ <http://www.ddialliance.org>

statistical office of the European Union), the International Monetary Fund (IMF), the Organisation for Economic Co-operation and Development (OECD), the United Nations (Statistics Division), and the World Bank. Although these standards were originally developed for the financial industry, because of their utility and interoperability they have found use for health data with the adoption of the Statistical Data and Metadata Exchange Health Domain⁹ (SDMX-HD). The World Health Organization maintains an Indicator and Metadata Registry (IMR) (31). These standards are useful for exchanging health data and the metadata describing health data.

Nine per cent of responding countries use the SDMX standards. Metadata standards have a much lower rate of adoption. This could be due to difficulty of implementation or perhaps due to the lack of awareness by, and training of, users in the systems controlling metadata standards.

Messaging standards

Overall, messaging standards have been widely adopted because of their clear utility in communicating health data. Examples are discussed below.

Health Level Seven (HL7)

HL7 is a framework of related messaging standards for the exchange and retrieval of electronic health information. This health information itself can be expressed in another standard such as the International Classification of Diseases (ICD), Systematized Nomenclature of Medicine (SNOMED), or Logical Observation Identifiers Names and Codes (LOINC) while HL7 provides a facility which improves functionality through the provision of “envelopes” to support the transport of HL7 messages from sender to receiver. These “envelopes” are called message wrappers. Level 7 [the application layer] of the Open Systems Interconnection [OSI] Communication Reference Model, developed by the International Organization for Standardization [ISO]]. HL7 version 3 is expressed in XML encoding syntax and allows the HL7 model to expand beyond messaging by including vocabularies from other sources. One example of this expansion is the development of the Clinical Document Architecture (CDA) which specifies the encoding, structure, and semantics of clinical documents for exchange.

There is a relatively high level of uptake of HL7, with 50% of the responding countries reporting having adopted it. This is due to the fact that the HL7 standard is built into most commercial health information software and therefore widely recognized.

Indicator Exchange Format (IXF)

The IXF is a reporting format that was developed for purposes of HIV/AIDS monitoring and evaluation. It was adopted by UNAIDS for use by the Country Response Information System (CRIS) software (32).

It was a precursor to the SDMX-HD format, which supports cross-organization indicator harmonization, international standards, and local customization, which are required for widespread adoption. While largely limited to HIV reporting, the IXF nonetheless established a precedent for non-proprietary, XML-based data exchange.

9 <http://www.sdmx-hd.org>

Thirty-four countries report using a version of CRIS; 14 others report being in the planning or piloting phase of CRIS implementation. Most users of the program are low or lower-middle income countries; they seek to build synergies, through data exchange, with other data management tools between sectors.

Only a very small percentage of responding countries (2%) report having adopted IXF. Survey respondents may not have realized that the CRIS software uses IXF and therefore underreported IXF use.

Medical record standards

Medical record standards are not widely utilized by responding countries, though, as the two examples discussed below reveal, a great deal of work is being done in this area.

ISO TC 215 and CEN/TC 251

ISO's Technical Committee (TC) 215 on health informatics works on health information and communications technology to facilitate interoperability of health data.

TC 215 consists of eight working groups dealing with various aspects of electronic health records. These include: data structure, data interchange, semantic content, security, pharmacy and medicines business, devices, business requirements for electronic health records, and standards development organization (SDO) harmonization. In addition, there are several task forces working in specialist areas. TC 215 has produced many standards and reports that are useful for implementing electronic health records.

The Comité Européen de Normalisation (CEN) TC 251 on health informatics works on standardization in the field of health information and communications technology in the European Union. Its goal is to achieve compatibility and interoperability of electronic medical record systems. A number of workgroups, each dealing with a specific aspect of the data, have been formed under TC 251. These include information models, terminology, security, and technology for interoperability. CEN TC 251 works closely with the ISO TC 215 to develop standards as well. Over the past few years these standards have addressed a wide range of interoperability issues for patient information and device communication as well as privacy and security issues related to patient data.

Fifteen per cent of the responding countries use this standard. This figure is relatively low and could indicate that countries may not have progressed far enough in the adoption of EMRs to perceive a need for use of these standards.

Vocabulary standards

Vocabulary standards compile and define the terms that describe medical conditions. Several nomenclatures exist, as shown in the examples below.

International Classification of Diseases (ICD)

The ICD is a list of codes to classify diseases, signs, symptoms, abnormal health findings and external causes of illness or injury (27). It has been maintained by WHO since the first World Health Assembly in 1948. This effort built on earlier classifications going back to the late 19th century.

The current version of the ICD is 10 although version 9 is still in widespread use, particularly in the USA. There have been several extensions and modifications of the ICD to provide better coverage of clinical conditions, health care procedures, and morbidity. The USA maintains the ICD-9-CM (Clinical Modifications) and is working on developing ICD-10-CM. ICD-9 contains approximately 17 000 codes whereas ICD-10 contains approximately 155 000 codes. WHO is currently working on ICD-11.

The ICD coding system is the standard most frequently used by responding countries, having been adopted by 82% of them.

Systematized Nomenclature of Medicine (SNOMED)

SNOMED was designed to provide a comprehensive nomenclature of clinical medicine for the purpose of describing records of clinical care in human medicine. It is a multi-axial and hierarchical classification system. It is multi-axial in that any given clinical condition can be described through multiple axes such as topography (anatomy), morphology, organisms such as bacteria and viruses, chemicals such as drugs, function (signs and symptoms), occupation, diagnosis, procedure, physical agents or activities, social context, and syntactic linkages and qualifiers. SNOMED is hierarchical in that each of the axes has a hierarchical tree that proceeds from general terms to more specific ones. For example topography (anatomic) terms are first divided into major organs such as lung, heart, and then into the smaller components of each.

The SNOMED CT is a collection of medical terms covering most areas of clinical information that is systematically organized to be processed by computer. It provides a terminology that is optimized to index, store, and retrieve clinical data across care boundaries and sites, and consists of over a million medical concepts. It is well suited for use in electronic medical records. (For more information, see Chapter 2.5.)

Twenty-five per cent of the responding countries have adopted SNOMED. This is much less than the ICD coding system and may be due to SNOMED's complexity. Cost is also likely to be an important factor in the relatively low uptake seen – the ICD is free and SNOMED is not.

Logical Observation Identifiers Names and Codes (LOINC)

LOINC¹⁰ is a standard for identifying medical laboratory observations. Developed by the Regenstrief Institute in the USA, it is specifically designed for use as an electronic database for clinical care and management that is suitable for use in an electronic health record. It has expanded from the original laboratory codes to include nursing diagnoses and interventions, outcomes classification, and a patient care data set.

LOINC is the preferred code set for HL7 laboratory test names in transactions. It currently contains over 58 000 observation terms.

A total of 23% of responding countries have adopted the LOINC standard.

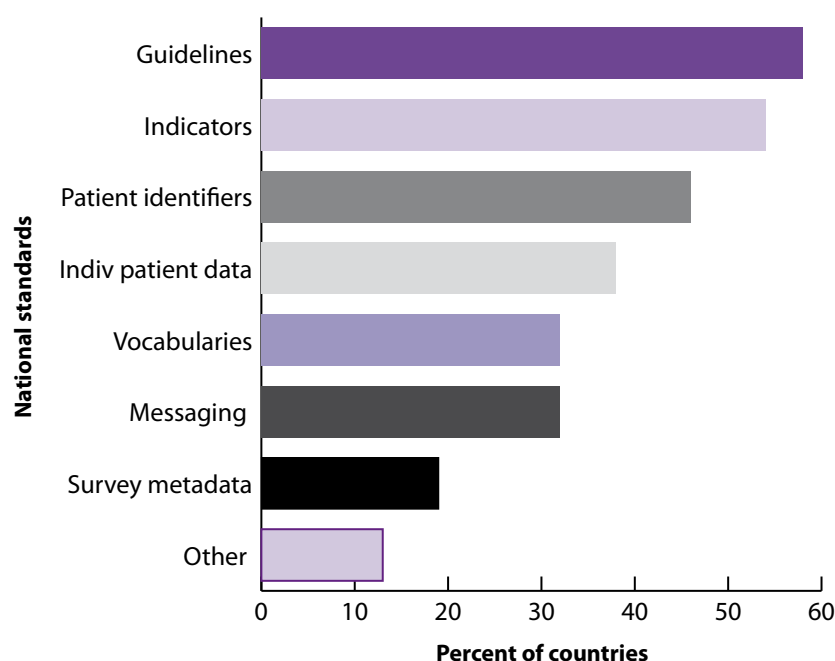
¹⁰ <http://loinc.org>

3.8 National adoption of standards

National leadership is important in defining standards for each category of health data for use in-country. National standards are usually based on the international standards discussed in the previous section, although often there will be modifications such as adoption of a subset or terms added. The adoption of a national standard requires broad consensus among the stakeholders who will be using it. This process typically takes considerable time and effort but has the benefits of improved information flow and better use of health data with better health outcomes as a result.

The survey investigated a group of common types of standards that might be adopted at the national level, which are shown in Figure 20. Often these are specific interpretations of the general standards discussed in the previous section.

Figure 20. Responding countries' adoption of selected national standards



Guidelines documents

Guidelines documents are designed to incorporate appropriate use of evidence, “best practices”, policies, and recommendations for concise directions which can be used as a reference by countries. They are a method of ensuring that nationally adopted procedures are followed. These can cover a wide variety of topics. In health they can also refer to procedures for collecting information, providing services, or working with development partners. Often the guideline documents will specify the use of national data sets or identifiers in order to improve the compatibility of health data.

Fifty-eight per cent of the responding countries use guidelines documents for national health data standards.

Standards for indicators used to monitor health and health systems

Most countries will have a national set of indicators which are used to monitor health status and health system performance. Often these indicators are drawn from international standards or from the monitoring and evaluation indicator sets of development partners or programmes. Usually these have a legacy of data and usage that means that they may not fully adhere to international standards. As long as the indicator sets are defined clearly, it is generally not useful to change these definitions since there is a risk of losing compatibility with historical data. However, if the definitions in the standards are not clear, changes to improve the clarity and precision of terms are useful.

Just over half of the responding countries (54%) have adopted national standards for health indicators.

Standards to identify patients

When dealing with individual patient data it is important to identify specific information so that the patient can be referenced uniquely and reliably. All systems that collect individual patient information use some method of identifying patients uniquely. Most systems will define a unique identifier that is local to the software application. Clinics and hospitals often have an identifier that is used throughout a system to transfer information such as clinical observations, laboratory and radiology results, and orders.

Health systems will often issue an ID card to the patient to facilitate timely access to patient records on subsequent visits. These may contain demographic, photographic or biomarker information to assist in accurately identifying patients.

Forty-six per cent of responding countries have adopted a patient identifier standard.

Individual patient data standards

Thirty-eight per cent of responding countries have standards for individual patient data. This can be anything from a small data set of demographic and basic clinical information to a complete longitudinal electronic medical record with full professional, laboratory, radiology and ancillary service input. Most commonly, countries have defined some set of individual patient data that is useful for continuity of care, monitoring and evaluation, or aggregate data for planning or research.

Examples of international individual patient data standards are the Continuity of Care Record (CCR) (33) and the Continuity of Care Document (CCD) (34); the latter is based on the Clinical Document Architecture (CDA) in use in the USA. The CCR was developed to facilitate transfer of the essential health record of an individual patient from one care provider to another through the use of a standard format and vocabulary. The CCD is a similar standard developed by the HL7 organization. The CDA is a more comprehensive method of representing patient clinical information, however. The CDA and CCD documents standards are specific to the US health care system but can be adopted for use elsewhere.

Vocabulary standards

Vocabularies provide a standard method of expressing health information. For clear communication it is vitally important to have each given health term precisely defined so that it will not lead to confusion or be subject to corruption when received. In Section 3.7 some standard vocabularies were discussed.

Vocabularies such as SNOMED or ICD are designed for specific descriptive purposes. A country may adopt these completely or agree to use subsets. Countries might find it useful to define their own vocabulary for a data set that is used within the country such as national health indicators, routine facility reporting, or monitoring and evaluation reporting.

Almost one third of the responding countries (32%) have adopted vocabularies in addition to ICD for use in their health sectors.

Messaging standards

Messaging is the electronic communication of health information from the point of collection or storage to a point of use. This can be a short distance such as within a clinic or larger distances across facilities or districts. Messages can be used to retrieve historical data as well as current data. A health message includes health data that is expressed in a standard vocabulary. It may also include metadata about the definitions or environment of the data. The message itself is in a precisely defined format so that it can be received by a computer program which will understand its meaning. HL7 is the most commonly used health message standard. Health software applications often use a proprietary or ad hoc messaging format that must be customized to be understood by both sender and receiver. These formats are usually only useful in a local context. The more messages that are sent and the more parties to receive these messages, the less useful proprietary or ad hoc message formats become; and standard message formats become more valuable in these instances.

Approximately one third of responding countries (32%) have adopted standards for health messages.

Survey metadata standards

Surveys are a valuable method of collecting health data. They usually identify a specific topic and a target population from which a sampling frame is drawn. They become more valuable when they are repeated over time or collect data using standards which allows comparison with other surveys. In order to compare survey data, it is necessary to have a standard set of metadata about the survey so that the complete context of the data, as well as the health data set definitions, are specified.

Only a relatively small percentage (19%) of responding countries have adopted standards for survey metadata. However, it is anticipated that uptake will increase as more countries realize the value of defining standards for survey metadata (e.g. reaping the benefits of having standard reference data about time and location).

3.9 Legal framework and adoption

By its nature health information is sensitive, particularly when it comes to individual health information. For this reason, it is important to have a clear legal framework for the collection, storage, disclosure, and use of health information.

The Global Observatory for eHealth published a volume in early 2012 titled *Legal frameworks for eHealth* (35) as part of the eHealth series, and a few of the findings relevant to patient information will be discussed here.

The majority of responding countries report having adopted legislation to ensure the privacy of personal health information. The details vary by country and context and also depend on whether the information is in electronic format, but it is clear that the majority of countries have realized the importance of personal health information privacy and have taken steps to formally integrate it into a legal framework.

Countries which have not as yet adopted formal protection report that it is high on their agenda and most of these countries expect to adopt individual person health information protection within the next few years.

Electronic patient records (either EMR or EHR) are a special form of electronic storage of personal health information that have only recently come into widespread use. It is important that this information be protected and many countries have adopted specific requirements for the handling of information in these records. Where countries have not adopted specific guidelines for EMR, it is assumed that the legal framework governing health information would apply.

3.10 Summary of key findings

- Most patient data are still being collected on paper in spite of the high costs, limited usefulness, and inefficiencies of this method.
- Countries in the upper-middle income and high-income World Bank groups have higher adoption of EMR/EHR systems than those in the lower two groups. This reflects their greater access to human and financial resources and ICT infrastructure.
- Use of electronic formats is higher for aggregated data than individual data. This can be due to the relative difficulty of implementing electronic formats for individual patient data, which require more complex software and training.
- High-income countries have transitioned to the point where there is today a higher use of electronic formats than paper records for patient data.
- Only a limited number of countries report widespread use of electronic formats coupled with electronic communications, the most advanced scenario polled. These are high-income countries which have advanced ICT infrastructure as well as a highly educated workforce.
- Electronic transmission use is similar to electronic capture rates which could be indicative of adoption of interoperable systems to communicate electronic data. The increasingly widespread availability of mobile telephone communications technology is an important asset which can stimulate the deployment of electronic patient health information.
- Globally, many countries collect aggregate health data in electronic formats at the national level indicating fairly widespread adoption of electronic systems for reporting at this level.
- Many countries have adopted standards for data interoperability and have national plans for implementation. Often these are based on international standards developed by international organizations such as UNAIDS, which creates the possibility of international comparisons and benchmarking of data.
- The survey illuminates active exploration and adoption of electronic tools for management of patient information. It is clear that most countries have recognized the potential of these technologies and, more importantly, taken steps to adopt them. In many cases adoption is widespread, including not only pilot programmes but full deployment of tools. However in other cases, adoption is constrained by lack of both human and financial resources. Significantly, countries have taken the institutional steps to ensure that adoption will proceed by developing the policy, strategy, and legal foundations for solid future growth of electronic records and their electronic transmission.



4

Conclusions



The survey results and supporting literature make a compelling case for the broad adoption of patient information systems in developed and developing countries. The survey results provide a clear picture of the current state of adoption across WHO regions and by World Bank income groups. They show that countries in the higher-income groups are more likely to be further advanced in the digitization of patient information than those in the lower-income groups. This is to be expected, as the process of digitization of records is highly dependent on, and linked to, the availability of human and ICT resources to which wealthier countries have greater access. Implementation of this crucial technology is not just reliant on available resources; national health system priorities and institutional will also play key roles in the successful implementation of patient information systems, which contributes to improved patient health, more efficient health care systems, and a more thorough understanding of disease.

4.1 Policy and strategy

The fifty-eighth World Health Assembly in May 2005 adopted resolution WHA58.28 establishing an eHealth strategy for WHO including specific reference to patient information systems, interoperability, and privacy of patient information and security (36).

The resolution urges Member States to

consider long-term strategic plans for the development and implementation of eHealth services including patient information systems. It calls on governments to form national eHealth bodies to provide guidance in policy and strategy, data security, legal and ethical issues, interoperability, cultural and linguistic issues, infrastructure, funding, as well as monitoring and evaluation. WHO recommends that Member States establish a national-level body for eHealth, supported by the ministry of health, as an instrument for implementing the WHA eHealth resolution. The body should include a division responsible for the governance of eHealth data interoperability standards and patient data privacy and security.

Member States rely on this resolution to provide high-level guidance for eHealth planning. Many also find that they need further information and request input from WHO offices to assist with the more detailed elements of strategy development and eHealth services planning including advice on patient information systems.

It is worth noting that WHO and the International Telecommunication Union (ITU) have jointly developed a comprehensive resource on eHealth strategy and planning. Among the components covered related to the management of patient information are data privacy, security, and interoperability. This unique resource, the *National eHealth Strategy Toolkit*, will be published in 2012 and will be made available to all Member States for planning, implementation, and evaluation of their eHealth strategies.¹¹

4.2 Framework for action

Both the survey and literature reveal the pressing need for investment in human resources and ICT infrastructure. The principles developed through research point the way to further development.

It is essential that Member States adopt data interoperability standards for the recording and communication of health information. Standards are crucial to ensuring that both the sender and receiver of data have the same definition and understanding of them. Without this understanding, health data communication is not reliable. WHO and its partners maintain a repository of indicator metadata to promote harmonization and management of indicators (37) for summary data. Individual patient clinical data can be standardized using the standards already covered in this publication. WHO further recognizes the important need for the development of patient health data privacy and security standards. Individual patient data must be protected from unauthorized disclosure. This requires the development and adoption of national regulations governing the collection, storage, and use of patient health data.

¹¹ <http://www.who.int/ehealth>

The collection of individual patient information permits the establishment of a longitudinal medical record which is invaluable for improving care of the individual as well as enhancing administrative, planning, and research functions. Electronic health information systems have been shown to be effective at improving the quality and efficiency of health services. They provide better information on which to make decisions that lead to improved outcomes, not only for the individual but also for administration and policy planning. The use of free open-source software to develop sustainable health informatics capacity may leverage the investment in developing such systems. Free open source software is particularly a boon to countries with financial constraints.

The survey demonstrates that the greatest barrier to adoption of patient information systems is the lack of resources. Human resources for implementation and training are the greatest cost of patient information systems. Free open-source software enables the development of sustainable local human resources for the implementation and maintenance of health information systems by drawing on a community of developers and users, all of whom share advances. Each project can benefit from the efforts of the community and, in turn, contribute to the community. This can lessen the demand for expensive external resources and enable the development of sustainable health information systems. Further, it can leverage the investment in trained human resources for maximum benefit.

A major and well recognized obstacle to the adoption of patient information systems, particularly in developing countries, is the lack of skilled health informatics professionals. By encouraging the development of a cadre of trained professionals, Member States will facilitate the adoption of health information systems. In time, these professionals can provide a sustainable bridge to improved use of health information and most importantly, better health.



5

References



1. *Electronic medical records*. The Office of the National Coordinator for Health Information Technology, United States Department for Health and Human Services (http://healthit.hhs.gov/portal/server.pt/community/electronic_medical_records/1219/home/15591, accessed 29 March 2012).
2. *Electronic health records*. Healthcare Information and Management Systems (http://www.himss.org/asp/topics_ehr.asp, accessed 29 March 2012).
3. *Personal health records. Definition and position statement*. Healthcare Information and Management Systems, 2007 (<http://www.himss.org/content/files/phrdefinition071707.pdf>, accessed 29 March 2012).
4. *Capability Maturity Model Integration*. Version 1.1. Pittsburgh, PA, Carnegie Mellon University, 2002.
5. Spewak SH & Hill SC. *Enterprise Architecture planning - developing a blueprint for data applications and technology*. Hoboken, NJ, John Wiley and Sons, 1993.
6. *NEHTA Interoperability Maturity Model*. Sydney, National eHealth Transition Authority, 2007 (<http://www.nehta.gov.au>, accessed 28 March 2012).
7. *HIMSS EMR adoption model*. Healthcare Information and Management Systems, (<http://www.himssanalytics.org>, accessed 28 March 2012).
8. *Fast facts on US hospitals*. American Hospital Association, 2011 (<http://www.aha.org/aha/resource-center/Statistics-and-Studies/fast-facts.html>, accessed 28 March 2012).

9. Canada EMR adoption model. Healthcare Information and Management Systems, 2012 (http://www.himssanalytics.org/hc_providers/emr_adoption.asp, accessed 28 March 2012).
10. Health information systems in developing countries: a landscape analysis. Vital Wave Consulting, 2009 (www.minsa.gob.pe/oegi/conferenciaops/Recursos/43.pdf, accessed 2 July 2012).
11. Chetley A. *Improving health, connecting people: the role of ICTs in the health sector of developing countries*. infoDev Working Paper No. 1, 2007 (www.infodiv.org, accessed 28 March 2012).
12. Brender J et al. Factors influencing success and failure of health informatics systems—a pilot Delphi study. *Methods of Information in Medicine*, 2006, 45(1):125-136.
13. Ruxwana NL et al. ICT applications as e-health solutions in rural healthcare in the Eastern Cape Province of South Africa. *Health Information Management Journal*, 2010, 39(1):17-26.
14. Evans DC, Nichol WP, Perlin JB. Effect of the implementation of an enterprise-wide electronic health record on productivity in the Veterans Health Administration. *Health Economics, Policy, and Law*, 2006;1(Pt 2):163-169.
15. Garrido T et al. Effect of electronic health records in ambulatory care: retrospective, serial, cross sectional study. *British Medical Journal*, 2005, 330(7491):581.
16. *Medical records manual: a guide for developing countries*. Geneva, WHO, 2006.
17. McKay MV, Douglas GP. *Touchscreen clinical workstations at the point of care: guiding protocols and managing data in Malawi*. Baobab Health unpublished observations, 2008.
18. Douglas GP et al. Using touchscreen electronic medical record systems to support and monitor national scale-up of antiretroviral therapy in Malawi. *PLoS Medicine*, 2010, 7(8):e1000319.
19. Weerawarana S, Weeratunga J. *Open source in developing countries*. Swedish International Development Cooperation Agency, 2004, (<http://www.eldis.org/fulltext/opensource.pdf>, accessed 1 June 2012).
20. Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. *British Medical Journal*, 2007, 335:330-333.
21. Wolfstadt et al. The effect of computerized physician order entry with clinical decision support on the rates of adverse drug events: a systematic review. *Journal of General Internal Medicine*, 2008, 23(4):451-458.
22. Kawamoto K, Houlihan CA, Balas EA. Improving clinical practice using clinical decision support systems. *British Medical Journal*, 2005, 330:765.
23. Cebul RD et al. Electronic health records and quality of diabetes care. *New England Journal of Medicine*, 2011, 365:825-833.

24. Dexter PR et al. Inpatient computer-based standing orders vs physician reminders to increase influenza and pneumococcal vaccination rates: a randomized trial. *Journal of the American Medical Association*, 2004, 292:2366-2371.
25. *mHealth: new horizons for health through mobile technologies*. Geneva, World Health Organization, 2011.
26. Brown JS et al. Distributed health data networks: a practical and preferred approach to multi-institutional evaluations of comparative effectiveness, safety, and quality of care. *Medical Care*, 2010, 48:S45-S51.
27. *International classification of diseases*. 10th edition. Geneva, World Health Organization, 1994 (<http://www.who.int/classifications/icd/en/>, accessed 28 March 2012).
28. *International classification of functioning, disability, and health*. Geneva, World Health Organization, 2001 (<http://www.who.int/classifications/icf/en/index.html>, accessed 28 March 2012).
29. *Monitoring and evaluation toolkit*. Geneva, Global Fund to Fight AIDS, Tuberculosis and Malaria, 2011 (<http://www.theglobalfund.org/en/me/documents/toolkit/>, accessed 28 March 2012).
30. *Guidelines on protecting the confidentiality and security of HIV information: proceedings from a workshop*. Geneva, UNAIDS, 2007.
31. *Indicator and metadata registry*. Geneva, World Health Organization, 2011 (http://www.who.int/gho/indicator_registry/en/, accessed 28 March 2012).
32. *Data exchange with the country response information system and UN agency software. A step by step guide*. Geneva, UNAIDS, 2006 (http://data.unaids.org/pub/BaseDocument/2007/cris_de_web_final_en.pdf, accessed 28 March 2012).
33. *Continuity of care record*. Version 2.1b. American Society for Testing and Materials/Massachusetts Medical Society/Health Information Management and Systems Society, 2012. [Concept paper](#), accessed 1 June 2012).
34. *Continuity of care document*. Health Level Seven, Inc./American Society for Testing and Materials, 2007 (http://www.hl7.org/documentcenter/public_temp_7B2DAF6A-1C23-BA17-oC61F642D7CB53E2/pressreleases/20070212.pdf, accessed 28 March 2012).
35. *Legal frameworks for eHealth*. Geneva, World Health Organization, 2012.
36. Resolution WHA 58.28. eHealth. In: Fifty-eighth World Health Assembly, Geneva, 16–25 May 2005. Geneva, World Health Organization, 2005 (http://apps.who.int/gb/ebwha/pdf_files/WHA58/WHA58_28-en.pdf, accessed 1 June 2012).
37. *WHO indicator and measurement registry*. Geneva, World Health Organization, 2011 (http://www.who.int/gho/indicator_registry/en/, accessed 28 March 2012).



71

MEDICAL

RESPONSE

U17 71H

Glossary



Bandwidth

A measure of the amount of data that can be transmitted per unit of time.

Computerized physician order entry (CPOE)

This is a system which allows physicians to enter orders for diagnostic and therapeutic actions directly into a computer for execution.

CCD

The Continuity of Care Document is a HL7 CDA compliant implementation of the CCR.

Clinical Document Architecture (CDA)

This was developed by the HL7 committee to describe the encoding, structure, and semantics of clinical documents for exchange.

CCR

The Continuity of Care Record is a patient health summary standard. It contains various sections such as patient demographics, insurance information, diagnosis and problem list, medications, allergies and care plan. It is formalized as a standard by the American Society for Testing and Materials.

Data

Data refer to raw, unedited observations.

Data dictionary

A specialized type of database containing metadata, which is managed by a data dictionary system. This centralized repository of information describes the characteristics of data used to design, monitor, document, protect, and control data in information systems and databases; it can also refer to an application of data dictionary systems.

Data management

A set of procedures to collect, store, analyse, and distribute data. Once data are collected, a sound management approach is essential. Firstly, a metadata dictionary is necessary to accurately describe the data elements. Next, effective data storage procedures require a well-designed logical structure to permit data retrieval and analysis. Data analysis and presentation include calculating indicators and preparing tables and graphs. Finally, the data should be made available to all those who can use and act upon them.

eHealth

eHealth refers to the use of information and communications technology for health.

GNI

Gross National Income is the total value of all that is produced within a country plus the net income from trade with other countries.

Health information system

A health information system includes the people, processes and technology to collect, communicate, manage, analyse, and present information for decision-making. It represents sources of population based data like census, vital events registration, surveys, as well as facility based data like individual health records, health service records, and resource management records. A health information system may be referred to as a health management information system or health management information system and is also likely to comprise any number of subsystems.

Information

Information is data which has been processed and organized into a meaningful output which can be used for decision-making or understanding concepts.

Information and communication technology (ICT)

Includes the computers, software, data-capture devices, wireless communication devices, and local and wide area networks that move information, and the people that are required to design, implement, and support these systems.

Interoperability

The ability of health information systems to exchange data in a semantically meaningful way, whether at the aggregate or patient level.

mHealth

Mobile eHealth or mHealth encompasses the use of mobile telecommunication and multimedia technologies as they are integrated within increasingly mobile and wireless health care delivery systems.

Open standards

Standards for information exchange that are freely available without restriction, e.g. open source software (also referred to as free and open-source software). The user has the freedom to:

- run the program for any purpose (freedom 0);
- study how the program works and adapt it (freedom 1);
- redistribute (adapted) copies to others (freedom 2); and
- improve the program and release those improvements to the public, for the benefit of the whole community (freedom 3).

Note that access to the source code is a precondition for all of these freedoms.

Metadata

Metadata is the information which describes data. Metadata is used to describe the definition, structure, and administration of data whereby the communication and use of those data are improved.



Appendix 1.

Methodology of the second global survey on eHealth



Purpose

The World Health Organization's eHealth resolution WHA 58.28 was adopted in 2005 and focused on strengthening health systems in countries through the use of eHealth (1); building public-private partnerships in ICT development and deployment for health; supporting capacity building for the application of eHealth in Member States; and the development and adoption of standards. Success in these areas is predicated on a fifth strategic direction: monitoring, documenting and analysing trends and developments in eHealth and publishing the results to promote better understanding. In direct response to the eHealth resolution, the Global Observatory for eHealth (GOe) was established to monitor and analyse the evolution of eHealth in countries and to support national planning through the provision of strategic information.

The GOe's first objective was to undertake a global survey on eHealth to determine a series of benchmarks at national, regional and global levels in the adoption of the necessary foundation actions to support the growth of eHealth. The aim was to provide governments with data that could be used as benchmarks for their own development as well as a way to compare their own progress with that of other Member States. The survey is part of the mandate defined during the GOe's inception – to provide Member States with reliable information and guidance on best practices, policies and standards in eHealth.

The second global survey on eHealth was conducted in late 2009 and was designed to build upon the knowledge base generated by the first survey. While the first survey conducted in 2005 was more general and primarily asked high-level questions at the national level, the 2009 survey was thematically designed

and presented more detailed questions. The thematic design of the survey has provided the GOe with a rich source of data that is being used to create a series of eight publications – The Global Observatory for eHealth Series – due for publication during 2010 and 2011.

Each publication in the series is primarily targeted to ministries of health, ministries of information technology, ministries of telecommunications, academics, researchers, eHealth professionals, nongovernmental organizations involved in eHealth, donors, and private sector partners.

Survey implementation

Based on the experience of the first global survey, the GOe benefited from many of the lessons learned in creating the second survey, disseminating the instrument in digital format, working with WHO regional offices and Member States to encourage survey completion, as well as processing the data and analysing the results.

Survey instrument

The instrument focused on issues relating to processes and outcomes in key eHealth areas. Objectives for the survey were to identify and analyse trends in the:

- uptake of eHealth foundation policies and strategies, building on the 2005 results;
- deployment of mHealth initiatives in countries;
- application of telemedicine solutions;
- adoption of eLearning for health professionals and students;
- collection, processing and transfer of patient information;
- development of legal and ethical frameworks for patient information in digital format;
- action concerning online child safety, Internet pharmacies, health information on the Internet, and spam; and
- governance and organization of eHealth in countries.

Table A1 shows the seven themes of the survey.

Theme	Action
mHealth	Identify the diverse ways mobile devices are being used for health around the world and the effectiveness of these approaches. Highlight the most important obstacles to implementing mHealth solutions. Consider whether mHealth can overcome the digital divide.
Telemedicine	Identify and review the most frequently used telemedicine approaches across the globe as well as emerging and innovative solutions. Propose necessary actions to be taken to encourage the global growth and acceptance of telemedicine, and particularly in developing countries.
Management of patient information	Describe the issues relating to the management of patient information at three levels – local health care facility, regional/ district, national levels. Analyse the trends in transition from paper to digital records. Identify actions to be taken in countries to increase the uptake of digital patient records.
Legal and ethical frameworks for eHealth	Review the trends in the introduction of legislation to protect personally identifiable data and health-related data in digital format as well as the right to access and control one's own record. Identify and analyse the control of online pharmacies by Member States. Review government action to provide for child safety on the Internet.
eHealth policies – a systematic review	Identify the uptake of eHealth policies across the globe and analyse by WHO region as well as World Bank income groups to establish possible trends. Systematically review the content and structure of existing strategies highlighting strengths and weaknesses. Propose model approaches for the development of eHealth policies including scope and content.
eHealth foundation actions	Review trends in the uptake of foundation actions to support eHealth at the national level including: eGovernment, eHealth, ICT procurement, funding approaches, capacity building for eHealth, and multilingual communications.
eLearning	Analyse the extent of use and effectiveness of eLearning for the health sciences for students and health professionals.
eHealth country profiles	Presentation of all participating Member States eHealth data aggregated by country to act as ready reference of the state of eHealth development according to selected indicators.

Table A1. Survey themes

Survey development

The survey instrument was developed by the GOe with broad consultation and input from eHealth. Planning for the 2009 global survey started in 2008 with the review of the 2005/2006 survey results, instrument and feedback from participating countries. One of the constraints identified in the first survey was on the management of data and its availability for compilation and analysis. In order to facilitate data collection and management, Data Collector (DataCol)¹² was used to make the survey instrument available online and therefore streamlining the collection and processing of data.

A set of questions was developed and circulated in the first quarter of 2009 for comments to selected partners in all regions through virtual teleconferences. The range of partners included those from government, WHO regional and country offices, collaborating centres and professional associations. Over 50 experts worldwide were involved in the process. Collaborative efforts extended to other WHO programmes as well as international organizations, such as the International Telecommunications Union (ITU) and Organisation for Economic Co-Operation and Development (OECD). An online forum to discuss the survey instrument and survey process was developed and hosted by the Institute for Triple Helix Innovation based at the University of Hawaii at Manoa in the United States of America.¹³

A draft questionnaire was developed and posted online for review by the partners and was pilot tested in March 2009 in five countries: Canada, Lebanon, Norway, Philippines, and Thailand. The final version of the survey instrument was enhanced based on the comments and observations received from the pilot testing. In order encourage countries to respond, the survey questions, instructions and data entry procedures were translated into all WHO official languages plus Portuguese.

Data Collector

Data Collector, DataCol, is a web-based tool that simplifies online form creation for data collection and management and is designed, developed and supported by WHO. The collected data are stored in a SQL database maintained by WHO database administrators, and can be exported as a Microsoft Excel file for further analysis using other statistical software.

This is the first time that DataCol has been used as the primary method of implementing an online survey of over 40 pages of text and questions. Significant preparation and testing was required to ensure that the system was robust and able to accommodate the data entry process from around the world, as well as the volume of data entered and stored online.

The various language versions of the survey instrument and supporting documentation were entered into DataCol by language. In addition, individual country login names and passwords were assigned to ensure that only one entry was submitted per country rather than multiple entries. Country coordinators were responsible for completing the forms after obtaining agreement from the expert informant group.

¹² Web-based tool for online creation of forms in surveys developed by WHO.

¹³ <http://www.triplehelixinstitute.org>

Preparation to launch the survey

One of the most important tasks in executing an international survey is to build a network of partners at the regional level who can liaise directly with countries. Due to differing priorities across WHO regions, not all regional offices have staff whose responsibilities included eHealth activities. For this reason many regional offices had to assign staff to assist in coordinating the survey process with countries in their respective region. Instructions for the survey procedures were circulated and were followed by a series of teleconferences.

One significant outcome during the survey implementation was the development of strong and productive working relationships with regional counterparts, without whom it would not have been possible to successfully undertake such a task. The success of the survey implementation can also be attributed to the assistance of regional and national office colleagues who worked directly with national counterparts in completing the questionnaire. Figure A1 shows the steps involved in survey process.

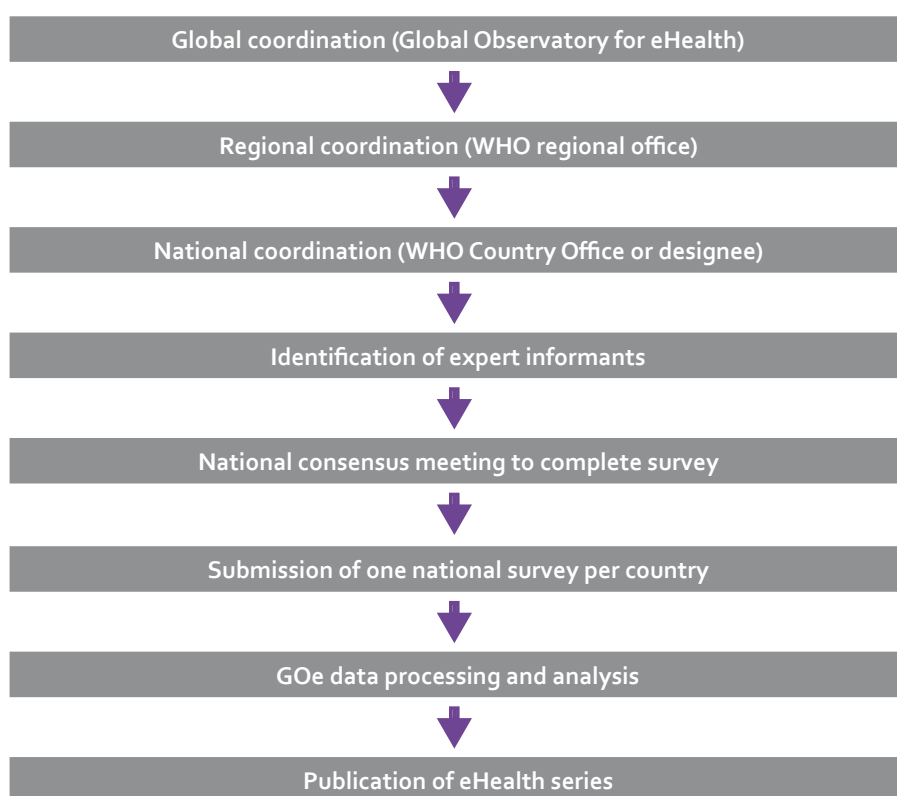


Figure A1. GOe survey and report process

Survey

The survey was launched on 15 June 2009, and due to the high level of interest, did not close until 15 December 2009. Regional focal points worked to encourage Member States to participate. In some cases this was easy; in others it required extensive discussions, not all of which were successful in achieving participation. Conducting a global survey is like conducting a campaign: the purpose and rewards of participation have to be conveyed to national coordinators and then to survey expert informants. It is important to build momentum and to maintain enthusiasm.

At the national level coordinators managed the task. Their responsibilities included finding experts in all of the areas addressed by the survey, and organizing and hosting a full-day meeting where the survey could be collectively completed by the entire group. The number of expert informants, per country, ranged from 5 to 15. The survey process helps build the GOe network of informants around the globe and now consists of over 800 eHealth experts.

Limitations

Member States were limited to one response per country; thus, the expert informants were required to come up with a single response for each question that was most representative of the country as a whole. Coming to a consensus could be difficult in cases where the situation varies widely within the country, or where there were significant differences in opinion. The survey does not attempt to measure localized eHealth activity at the subnational level.

The survey responses were based on self-reporting by the expert informant group for each participating Member State. Although survey administrators were given detailed instructions to maintain consistency, there was significant variation across Member States in the quality and level of detail in the responses, particularly to for the descriptive, open-ended questions. While survey responses were checked for consistency and accuracy, it was not possible to verify the responses for every question.

The scope of the survey was broad, and survey questions covered diverse areas of eHealth – from policy issues and legal frameworks to specific types of eHealth initiatives being conducted in-country. Every effort was made to select the best national experts to complete the instrument; however, it is not possible to determine whether the focus groups had the collective eHealth knowledge to answer each question. While the survey was circulated with a set of detailed instructions and terminological definitions, there is no guarantee that these were used when responding.

Data processing

On receipt of the completed questionnaires, all non-English responses were translated into English. Survey responses were checked for consistency and other errors, and countries were contacted for follow-up to ensure accurate reporting of results. Data were exported from DataCol in Microsoft Excel format and the data analysis was performed using R statistical programming language.¹⁴

Data were analysed by thematic section. For closed-ended questions, percentages were computed for each possible response to obtain the global level results. In addition, the data were aggregated and analysed by WHO region and World Bank income group to see trends by region and by income level. Preliminary analysis based on aggregation by ICT Development Index showed similar results as for World Bank income group (2). This is due to the high correlation between ICT Development Index and GDP per capita (Spearman $\rho=0.93$, $p=10^{-16}$). Therefore, these results were not included in this report. Cross-question analysis was performed where two or more questions were thought to be related, and the results were probed in greater depth as warranted. External health and technology indicators, such as mobile phone penetration, were introduced into the analysis for comparison purposes where relevant.

Results from the current survey were compared to those from the previous survey wherever possible; however, as the subject matter covered by the 2009 survey was considerably broader, and the survey questions were worded somewhat differently, there was little scope for this sort of analysis. In addition, the percentages were often not directly comparable, particularly at the regional level, as the sets of responding countries were different, and the expert informants in each iteration of the survey were also different.

Table A2 shows the advantages and disadvantages of the groupings used in the survey.

Country grouping	Advantages	Disadvantages
WHO region	WHO regional approach integrated into WHO strategic analysis and planning, and operational action.	Limited country commonality from an economic, health care, or ethnic perspective. Less useful for other agencies or institutions wishing to interpret or act on GOe data.
World Bank income group	Clear economic definition based on GNI per capita. Consistent application of criteria across all countries. Simple four-level scale.	Does not account for income disparity, ongoing armed conflicts, health of the population, or population age.

Table A2. Advantages and disadvantages of the country groupings

¹⁴ See for more information <http://www.r-project.org/>.

Response rate

The “Management of patient information” section of the survey, on which this publication is based, was completed by a total of 114 countries (59% of all WHO Member States). Figure A2 shows the responding Member States for this module of the survey. Tables A3 and A4 show the distribution of the responding countries by WHO region and World Bank income group.

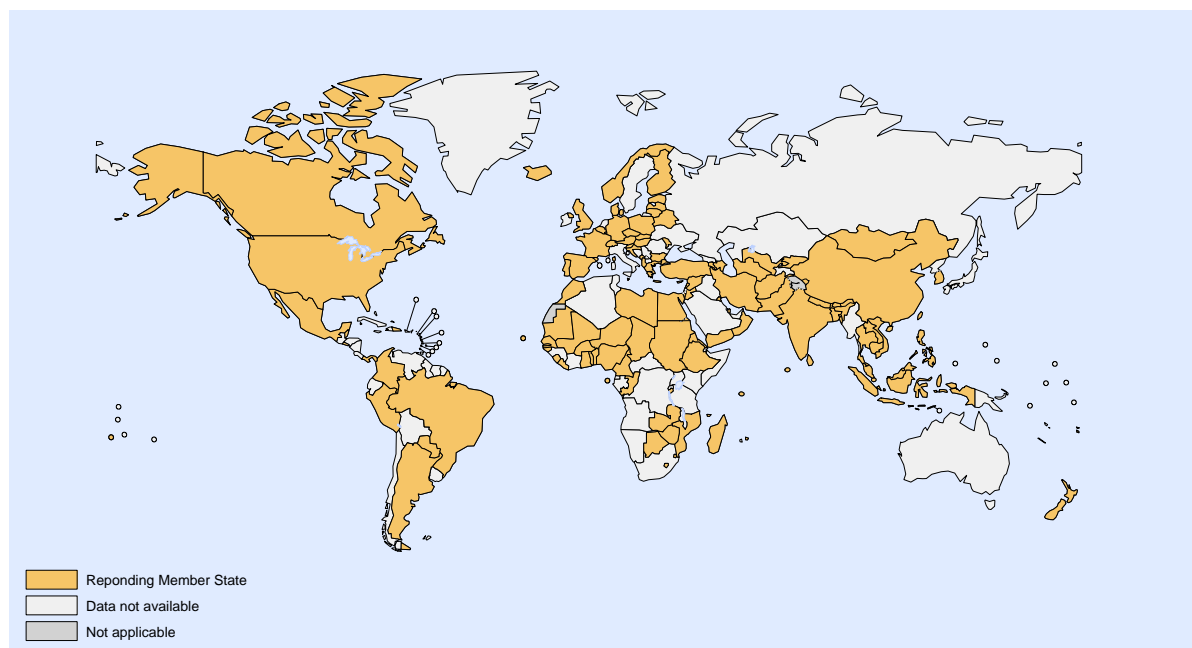


Figure A2. Responding Member States

Response rate by WHO region

Administratively WHO is made up of six geographical regions, which are quite heterogeneous: Member States differ with respect to size, economy, and health care challenges. Nevertheless, it is still important to present high-level eHealth analyses at the regional level as this reflects the organizational structure and operational framework of WHO.

A breakdown by WHO regional responses is presented in Table A3. It shows considerable variation ranging from 34% for the Americas to 73% for the South-East Asia Region. Numerous Member States, particularly those in the Region of the Americas, indicated that they would not be able to participate in the 2009 survey due to resources being diverted to prepare and respond to the H1N1 pandemic or due to other urgent public health issues such as conflict situations. The Western Pacific Region has many small island Member States of which only a few responded to the survey, yielding a response rate of 48% for the region. The response rates for the Eastern Mediterranean, African, and European Regions were over 60%. This was particularly encouraging for regions consisting of a large number of Member States such as the African and European Regions. Results from regions with low response rates should be interpreted with care as they may not be representative of the entire region.

	WHO region					
	African	Americas	South-East Asia	European	Eastern Mediterranean	Western Pacific
Total number of countries	46	35	11	53	21	27
No. of responding countries	29	12	8	36	14	13
Response rate	63%	34%	73%	68%	67%	48%

Table A3. Response rate by WHO region

For the South-East Asia Region, although the number of responding countries was the lowest, the response rate was the highest since the region consists of a total of 11 Member States. Self-selection of the sample often occurs in surveys of this nature, where responding countries are more likely to have a high level of interest and/or activity in eHealth. Table A4 shows that response rates in low and lower-middle income brackets were high. Past surveys have shown that countries in these groups generally have less eHealth activity in comparison to high and upper middle-income brackets. Thus, in some cases, Member States participating in the survey may reflect a commitment to moving forward with eHealth.

Response rate by World Bank income group

The World Bank classifies all economies with a population greater than 30 000 into four income groups based on gross national income (GNI) per capita.¹⁵ The classification is as follows: low income (US\$ 975 or less), lower-middle income (US\$ 976–3855), upper-middle income (US\$ 3856–11 905), and high income (US\$ 11 906 or more). These income groups are a convenient and practical basis for analysis, enabling a review of trends in the survey results based on income level. Classification by income does not correspond exactly to level of development; however, low and middle-income countries are sometimes referred to as 'developing' economies and high-income countries as 'developed', for convenience.

Table A4 shows the survey response rate by World Bank income group. Low-income countries had the highest response rate (70%), closely followed by high-income countries (63%). In terms of raw numbers, the distribution of responding countries was remarkably even, with 30 to 31 countries responding from the high-income, lower-middle income, and low-income groups, and a slightly lower number of countries from the upper-middle income group.

	World Bank income group			
	High income	Upper-middle income	Lower-middle income	Low income
Total no. countries	49	44	53	43
No. of responding countries	31	21	30	30
Response rate	63%	48%	57%	70%

References

1. Resolution WHA 58.28. eHealth. In: *Fifty-eighth World Health Assembly, Geneva, 16–25 May*. Geneva, World Health Organization, 2005 (http://apps.who.int/gb/ebwha/pdf_files/WHA58/WHA58_28-en.pdf, accessed 18 May 2011).
2. *Measuring the information society – the ICT Development Index*. Geneva, International Telecommunications Union, 2009 (<http://www.itu.int/ITU-D/ict/publications/idi/2009/index.html>, accessed 17 May 2011).

¹⁵ <http://data.worldbank.org/about/country-classifications>.



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