Appendix

Legal frameworks for eHealth

Based on the findings of the second global survey on eHealth

Global Observatory for eHealth series - Volume 5
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.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>mHealth</td>
<td>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.</td>
</tr>
<tr>
<td>Telemedicine</td>
<td>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.</td>
</tr>
<tr>
<td>Management of patient information</td>
<td>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.</td>
</tr>
<tr>
<td>Legal and ethical frameworks for eHealth</td>
<td>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.</td>
</tr>
<tr>
<td>eHealth policies – a systematic review</td>
<td>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.</td>
</tr>
<tr>
<td>eHealth foundation actions</td>
<td>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.</td>
</tr>
<tr>
<td>eLearning</td>
<td>Analyse the extent of use and effectiveness of eLearning for the health sciences for students and health professionals.</td>
</tr>
<tr>
<td>eHealth country profiles</td>
<td>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.</td>
</tr>
</tbody>
</table>

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)\(^1\) was used to make the survey instrument available online 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.\(^2\)

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 to 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.

---

1. Web-based tool for online creation of forms in surveys developed by WHO.
2. [http://www.triplehelixinstitute.org](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 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.3

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 ρ=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.

<table>
<thead>
<tr>
<th>Country grouping</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHO region</td>
<td>WHO regional approach integrated into WHO strategic analysis and planning, and operational action.</td>
<td>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.</td>
</tr>
<tr>
<td>World Bank income group</td>
<td>Clear economic definition based on GNI per capita.</td>
<td>Does not account for income disparity, ongoing armed conflicts, health of the population, or population age.</td>
</tr>
<tr>
<td></td>
<td>Consistent application of criteria across all countries.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Simple four-level scale.</td>
<td></td>
</tr>
</tbody>
</table>

Table A2. Advantages and disadvantages of the country groupings

3 See for more information http://www.r-project.org
Response rate

The “Legal frameworks for eHealth” module of the survey, which this publication is based on, was completed by a total of 113 countries (59% of all WHO Member States). Figure A2 shows the distribution of 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.

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

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. The classification is as follows: low income (US$ 975 or less), lower-middle income (US$ 976–3,855), upper-middle income (US$ 3,856–11,905), 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.

<table>
<thead>
<tr>
<th>World Bank income group</th>
<th>Total no. countries</th>
<th>No. of responding countries</th>
<th>Response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>High income</td>
<td>49</td>
<td>31</td>
<td>63%</td>
</tr>
<tr>
<td>Upper-middle income</td>
<td>44</td>
<td>21</td>
<td>48%</td>
</tr>
<tr>
<td>Lower-middle income</td>
<td>53</td>
<td>30</td>
<td>57%</td>
</tr>
<tr>
<td>Low income</td>
<td>43</td>
<td>30</td>
<td>70%</td>
</tr>
</tbody>
</table>

Table A4. Response rate by World Bank income group

References