Meeting Report

Workshop on IT Solutions for Health Research Governance and Management in the Western Pacific Region

Hanoi, Viet Nam
11-12 November 2013

World Health Organization
Western Pacific Region
Participants of the Workshop on IT Solutions for Health Research Governance and Management in the Western Pacific Region
Hanoi, Viet Nam, 11–13 November 2013
REPORT

WORKSHOP ON IT SOLUTIONS FOR HEALTH RESEARCH GOVERNANCE AND MANAGEMENT IN THE WESTERN PACIFIC REGION

Convened by:

WORLD HEALTH ORGANIZATION
REGIONAL OFFICE FOR THE WESTERN PACIFIC

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NOTE

The views expressed in this report are those of the participants of the Workshop on IT Solutions for Health Research Governance and Management in the Western Pacific Region who attended the meeting and do not necessarily reflect the policy of the World Health Organization.

This report has been prepared by the World Health Organization Regional Office for the Western Pacific for governments of Member States in the Region and for participants in the Workshop on IT Solutions for Health Research Governance and Management in the Western Pacific Region, which was held in Hanoi, Viet Nam from 11 to 12 November 2013.
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Keywords: 
- Health Information management  
- Research  
- Access to information  
- Health personnel – education  
- Telemedicine
**LIST OF ACRONYMS**

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<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>API</td>
<td>Application programming interface</td>
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<tr>
<td>CHRERC</td>
<td>College Health Research Ethics Review Committee (Fiji)</td>
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<td>DHS</td>
<td>Division of Health Sector Development</td>
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<td>ECUHS</td>
<td>Ethics Committee of the University of Health Science (Lao P.D.R.)</td>
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<td>ERC</td>
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<td>FNU</td>
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<td>HERDIN</td>
<td>Health Research and Development Information Network (Philippines)</td>
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<td>HKM</td>
<td>Health knowledge management</td>
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<td>HSPH</td>
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<td>HRP</td>
<td>Health Research Portal</td>
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<td>IER</td>
<td>Health Information, Evidence and Research</td>
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<td>IRB</td>
<td>Institutional Review Board</td>
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<td>IT</td>
<td>Information Technology</td>
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<td>Lao P.D.R.</td>
<td>Lao People's Democratic Republic</td>
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<td>MIT</td>
<td>Massachusetts Institute of Technology</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>NADA</td>
<td>National Data Archives</td>
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<td>NEC</td>
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<td>NECHR</td>
<td>National Ethical Committee for Health Research (Cambodia and Lao P.D.R.)</td>
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<td>NER</td>
<td>National electronic registry (Mongolia)</td>
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<td>National Institute Of Public Health (Lao P.D.R.)</td>
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<td>NIPH</td>
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<td>PCHRDP</td>
<td>Philippine Council for Health Research and Development</td>
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<td>PHREB</td>
<td>Philippines Health Research Ethics Board</td>
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<td>PNHRS</td>
<td>Philippine National Health Research System</td>
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<td>SOP</td>
<td>Standard Operating Procedure</td>
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<td>UHS</td>
<td>University of Health Sciences (Cambodia and Lao P.D.R.)</td>
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<td>WHO</td>
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<td>WPRIM</td>
<td>Western Pacific Region Index Medicus</td>
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<td>WPRO</td>
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SUMMARY

Problems in health research management and governance and the Health Research Portal (HRP)

The Western Pacific Region is the fastest-growing region of the World Health Organization (WHO) in terms of health research, increasing its share of global research production by more than 30% from 1992 to 2006. However, there are several barriers to unlocking the full potential of health research to generate better health. One of these barriers is comprised by suboptimal management and governance systems which makes it difficult for stakeholders (funders, users and researchers) to assess the status of ongoing research. This potentially leads to duplication of research, non-reporting and non-use of findings, and waste of resources. The lack of health research management and governance is also a key knowledge management issue in the Region.

As in many other areas of health, Information Technology (IT) solutions have substantial potential to improve health research governance and management, including knowledge management. Since the beginning of 2012, the WHO Regional Office for the Western Pacific (WPRO) has led the development and introduction of an IT-based integrated health research governance and management tool, also referred to as the Health Research Portal (HRP). The HRP offers an online system for ethics approval procedures. When researchers are required to submit their research proposals for ethics approval via the HRP, the HRP offers several important benefits:

- It links several systems and stakeholders: researchers, regulatory system such as ethics review and approval systems, and national health research coordinators and managers.

- Its outputs include a publicly accessible health research registry, a research reports repository, a researcher directory, and meta-information on total research investments by source and research type and other critical data.

- Standardization and harmonization of review and approval procedures across research ethics review committees in the country.

The Regional Office provided technical assistance to develop and apply an HRP in six countries: Cambodia, Fiji, the Lao People’s Democratic Republic (Lao P.D.R.), Mongolia, Philippines and Viet Nam. The objectives of this workshop were:

1. to take stock of the progress made by different countries and share experiences in implementing the HRP;

2. to help in developing peer solutions to address the challenges faced; and

3. to identify mechanisms to further support and sustain the use of IT solutions for better health research management.

**Status of implementation of the HRP**

All six countries are at different stages of implementation of the HRP:

- **Lao P.D.R.:** HRP is functional and being used (only the basic functions); more work is needed to make use of its full potential.

- **Cambodia:** HRP software platform is ready; the country must now wait for accompanying policy changes and Standard Operating Procedures (SOPs); it hopes to have the HRP
launched by Feb 2014 with requirement of online submission of research proposals for ethics review.

- Fiji: HRP software platform is ready and installed on the server of the Ministry of Health (MOH); a draft SOP and research guidelines have been prepared; a stakeholder consultation has been organized; launch of the HRP is planned for Nov/Dec 2013.

- Philippines: Pilot-version of the HRP is functional but it is not yet being used; piloting with several Ethics Review Committees (ERCs) is underway; several policy issues are being sorted out.

- Viet Nam: HRP is functional but not yet being used; it is planned to be piloted at an institutional level first (at the Hanoi School of Public Health (HSPH)).

- Mongolia: There is a strong interest for adopting the HRP from the Mongolian MOH; initial consultation with MOH is planned in Nov 2013 with technical assistance visit from WPRO/WHO; launch of the HRP is planned by January 2014.

Challenges in the implementation of the HRP

Key challenges in the implementation of the HRP were identified as part of the workshop. These challenges fell into five broader categories:

- Policy and regulatory frameworks: The absence of policy frameworks to steer ERCs in adopting the HRP.

- Limited capacity for ethics review and approval: Limited human and financial resource capacity at the ERC.

- Technical challenges: IT capacity, IT infrastructure, internet connectivity.

- User concerns: Users concerns about security, confidentiality, transparency, limited IT expertise of researchers/ethics review.

- Ownership and leadership: Limited interest from high-level policymakers in committing resources for this purpose in the context of predominantly externally funded research.

Taking it forward: next steps

Each country developed its own action plan for improving the national system for health research and management, in particular furthering the implementation of the HRP. However, several recommendations that were common to all countries emerged:

- Consider establishing National Health Research Advisory Committees (not just an Ethics Review Committee), or other initiatives with membership from different stakeholders that may provide momentum for improvements to the national health research and management systems.

- Work towards establishing national policies for health research management where such policies do not exist.

- Take national ownership over the country’s health research, and be actively involved in assessing what is needed to improve the national health research and management system, and communicate those needs to different partners, including WHO, if external help is needed.
• Address remaining technical challenges.

In addition, countries should consider additional potential solutions/systems to improving health research management and governance, such as: open access institutional/national repositories for published research articles; microdata repositories, particularly the National Data Archives (NADA) tool; and local literature databases to improve archiving and access to local non-English literature (such as the Philippine Health Research and Development Information Network (HERDIN) and MongolMed).

Finally, the workshop recommended that WHO WPRO should monitor the implementation of the action plans of the six countries that were present at this workshop.
The Workshop on IT Solutions for Health Research Governance and Management in the Western Pacific Region was held at the Hanoi School of Public Health in Hanoi, Viet Nam from 11 to 12 November 2013.

1. Objectives

(1) To take stock of the progress made by different countries and share experiences in implementation of IT-based solutions for health research governance and management.

(2) To help in developing peer solutions to address the challenges faced.

(3) To identify mechanisms to further support and sustain the use of IT solutions for better health research management.

1.2 Organization

The workshop was convened by the Health Information, Evidence and Research unit of the Division of Health Sector Development, WHO Regional Office for the Western Pacific. Dr Manju Rani, Senior Technical Officer, Health Research Policy, served as the responsible officer from the WHO Secretariat. Session chairpersons and moderators were selected from the participants. Mr Rik Viergever served as rapporteur for the meeting. Annex 1 provides the meeting agenda and detailed programme.

1.3 Participants and resource persons

The workshop was attended by 26 participants and observers. Of these, 23 came from six countries – Cambodia, Fiji, the Lao People’s Democratic Republic, Mongolia, the Philippines and Viet Nam – that are in the process of adopting the health research portal (HRP), a new online system for health research management, or have concrete plans to implement the system. In addition, two representatives from the WHO Regional Office for the Western Pacific and two representatives from WHO Country Office for Viet Nam formed the Secretariat. The list of participants, temporary adviser, consultant, observers and Secretariat is attached as Annex 2.

1.4 Opening remarks

Dr Tran Huu Bich, Vice-Dean of the Hanoi School of Public Health, opened the meeting and welcomed participants.

He stated that the countries represented at this workshop have made several attempts to harmonize and standardize approaches to research governance and data sharing and emphasized the importance of countries working together in these efforts. Referring to the Expert Consultation on Improving Health Research Management, Governance and Data Sharing in the Western Pacific, convened by the WHO Regional Office for the Western Pacific in 2011, he expressed his appreciation for the lead taken by WHO in conceiving, conceptualizing and supporting IT solutions for health research governance and management. He thanked the participants for their time and participation in the workshop.

Dr Socorro Escalante from the WHO Country Office for Viet Nam welcomed the participants on behalf of the WHO Representative, Dr Takeshi Kasai. She thanked Dr Bich and the Hanoi School of Public Health for organizing this workshop. She mentioned that health research is essential to
universal health coverage. However, problems with research governance and management in many countries have resulted in poor quality and underutilization of health research. In addition, there are growing concerns about research transparency, which is vital to increase the accountability of researchers.

IT solutions such as HRP can help to increase both transparency and accountability in health research. Additionally, IT-based systems have the potential to improve the management of health research. She congratulated the six countries in attendance for being among the early adopters of HRP. She expressed hope that these countries would further develop this system, ultimately resulting in increased accountability, transparency and quality in health research in these countries.

She concluded by stating that this workshop will be an excellent opportunity for sharing experiences, and furthering the development and implementation of HRP.

2. PROCEEDINGS

2.1 Session 1: Setting the scene: How can IT facilitate better and more efficient health research?

**Title**: Challenges in health research systems: potential role of IT solutions

**Presenter**: Dr Manju Rani, WHO Regional Office for the Western Pacific, Manila

Dr Rani presented four key challenges in health research management and governance that constrain the optimum return on health research investments (Figure 1).

1. Unknown research investments and inaccessible research outputs: Many countries face difficulties in monitoring health research investments (i.e. who is spending and on what and how much) and their impact. They also face challenges in establishing systems to ensure access to health research outputs.

2. Issues in operationalizing priority setting: In response to global advocacy for priority setting in health research at the national level since 1990s, many priority-setting tools and methods have been developed, and many developing countries, such as the Lao People’s Democratic Republic, Malaysia, Papua New Guinea and the Philippines, have tried to set up a national health research agenda and establish priorities. However, the impact of these priority-setting exercises on influencing the research landscape is unclear. A predominance of external funding, limited information on ongoing research and non-existent systems to share information across multitude of research organizations and funders have constrained the operationalization of priority health research agendas.

3. Research wastage: Poor accountability and transparency have led to substantial research wastage due to irrelevant research, poor/inappropriate methodologies, failure to report results in accessible and usable form, and selective non-reporting.

4. Weak and inefficient regulatory and approval systems for health research: The approval systems are either non-existent or overly centralized, complicated and uncoordinated.
The predominance of external funding of health research (which in turn implies limited ownership of the investments made) provides few incentives to governments in developing countries to create and shoulder the cost of governance solutions to monitor these research investments. Therefore, national ownership, stewardship and establishment of national systems for health research governance and management are critical.

A new online integrated health research management system – health research portal (HRP) – was conceptualized by the WHO Regional Office for the Western Pacific in 2011 as a potential solution to these problems. The Regional Office used it first as a tool for management of research sponsored and funded by the Organization. Subsequently, HRP was offered to six countries to take the lead in piloting it at the national level. Since the premise has always been to enable each country to have its own unique system, HRP is customizable to meet the needs of each country.

The HRP offers several potential benefits for all the stakeholders in health research (Figure 2).

1. It links regulatory systems (e.g. ethics review systems and approval systems) and stakeholders (e.g. researchers, national health research coordinators and managers).

2. Its outputs include a publicly accessible health research registry, a research repository, a researcher directory, and meta-information on total research investments by source and research type and other critical data.

3. It forces standardization and harmonization of review and approval procedures across research ethics review committees in the country.

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Figure 1. The disadvantages of not having an effective system for health research governance and management

- Inaccessible research outputs
- Unknown research investments
- Substantial research wastage
- Uncoordinated & Inefficient research approval systems
- Limited Accountability & transparency in research
Transitional to this new online system for research management and governance at country level requires national ownership and substantial coordination across multiple stakeholders. Governments must feel compelled to improve accountability and transparency in health research, must take the initiative in setting up such a system, and must take ownership of the system. Furthermore, as the system is linked with regulatory processes, governments must develop national policies and guidelines that govern all researchers and ethics review committees. This is currently not the case in all countries, where ethics review committees sometimes appear to be independent bodies, instead of being part of a national health research system.

The Lao People’s Democratic Republic was the first of six countries to launch HRP (www.laohrp.com), all of which are at different stages of implementation. This workshop was organized to assess the progress made in implementing HRP in each of these countries, to identify the challenges that lie ahead, and to develop a plan for moving forward.

2.2 Session 2: Country reports

Five countries – the Lao People’s Democratic Republic, Cambodia, Fiji, the Philippines and Viet Nam – presented their experience with and progress made in setting up HRP.
2.2.1 Lao People’s Democratic Republic

**Title:** Adoption of the national health research portal: experience of the Lao People’s Democratic Republic

**Presenter:** Dr Boupha Thongmalayvong, National Institute of Public Health, Lao People’s Democratic Republic

**Status of the implementation of HRP**

The Lao People’s Democratic Republic launched HRP in December 2012 following several rounds of national consultations with important stakeholders. Before launching the online system, training was provided to the secretariat of the National Ethical Committee for Health Research (NECHR) and the Ethics Committee of the University of Health Sciences (ECUHS) – the two functional ethics review committees in the country. The stakeholder consultations and training were facilitated by the WHO Regional Office for the Western Pacific and the National Institute of Public Health. The WHO Regional Office also provided technical support to customize and install the system.

During the first six months of operation, the National Institute of Public Health struggled with irregular Internet connection and intermittent power supply to the server. Hence, a decision was made to host the system on an outside server. The information on HRP was disseminated to wider research communities during two national health research symposiums in 2012 and 2013. The NECHR secretariat provides assistance to researchers facing problems with online submission. Not all functionalities of the system are currently used (e.g. generating annual reports and assignment of reviewers is yet to be used by Ethics Review Committee.).

**Status summary:** HRP is functional and is being used (only the basic functions); more work is needed to make use of its full potential.

**Main challenges in the implementation**

The Lao People’s Democratic Republic is facing the following challenges in the implementation of HRP:

- lack of clear regulatory framework, organizational responsibility on governance and management of the system;
- dependence on technical support from the WHO Regional Office to modify the system to accommodate NECHR’s needs;
- stakeholders’ concerns surrounding confidentiality and security of the data (Intellectual Property right and issues);
- limited and unreliable access to the Internet experienced by users of the system; and
- The Research Ethics Committee at University of Health Sciences does not use HRP yet, although the secretariat has been trained.

The country is in the process of developing a national health research strategy to improve health research quality, access to and use of research, and research data availability. It will also serve as an important enabler of this new system.
Envisioned next steps

The next steps in developing the system are envisioned to be:

- continue to develop the system to take advantage of its full potential.
- make use of the monitoring function of HRP by reporting the research that is conducted in the Lao People’s Democratic Republic by research type and source of funding (external and internal); and
- use the system to disseminate information on health research in the country, including research policies, guidelines, research grants or other events.

2.2.2 Cambodia

**Title**: Improving health research governance/management and access to health research outputs in Cambodia: experience, issues and progress made

**Presenter**: Dr Ir Por, National Institute of Public Health, Cambodia

**Status of the implementation of HRP**

A national consultation workshop on the establishment of HRP in Cambodia was held in January 2013. The system was installed on a server in August 2013. Two IT persons from Cambodia’s NECHR have been partially trained to test and run the system. Modifications are being made to the system according to specific recommendations by NECHR – the only ethics review committee in the country. The adoption of HRP requires a revision of the standard operating procedures (SOPs) for NECHR’s ethical review. The SOPs are being developed and are expected to be finalized in December 2013. Cambodia hopes to launch the system in February 2014 with a requirement for online submission. That may require further training and testing with volunteer researchers.

**Status summary**: The HRP software platform is ready; the country must now wait for finalization of accompanying policy changes and SOPs; the formal launch is planned for February 2014.

**Main challenges in the implementation**

Cambodia is facing the following challenges in the implementation of HRP:

- delays in the revision of NECHR SOPs, a precondition to adoption and use of HRP;
- modifications to the system to accommodate NECHR’s recommendations;
- limited IT capacity of NECHR secretariat, specifically no IT staff and limited IT infrastructure (server and Internet issues);
- no HRP user’s guide in Cambodia;¹ and
- no security or back-up system in place.

¹A generic user’s guide for HRP is available in English (developed by the WHO Regional Office for the Western Pacific).
Envisioned next steps

The next steps in developing the system are envisioned to be:

- speed up the revision of SOPs to be finalized in December 2013;
- start training and testing the system with a few volunteer researchers in December 2013 and January 2014;
- start using the system in February 2014, mainly for proposal submission and ethical review function;
- convene a launching workshop and distribute a mass email announcement to all researchers;
- communicate one-on-one with researchers who may contact the NECHR secretariat for proposal submission;
- if necessary, maintain the hard-copy submission approach as an alternative for researchers who are unable to submit proposals online; and
- gradually extend utilization of other functions of the system, such as archiving and information sharing, and network and communication.

2.2.3 Fiji

Title: Reforming health research management in Fiji

Presenter: Mr Rajneshwar Prasad, Ministry of Health, Fiji

Status of the implementation of HRP

A consultation was held on the implementation of HRP, and trainings were conducted for potential users. Several meetings were held to demonstrate and increase awareness of the system among potential users. A manual has been developed. The HRP is included in the Research Policy and SOPs of the National Health Research Committee of the Ministry of Health (but not yet in the SOPs of the three institutional ethics review committees in the country). The final endorsement/approval of the system is expected soon.

Status summary: The HRP software platform has been installed on the server of the Ministry of Health; draft SOPs and research guidelines have been prepared; a stakeholder consultation has been organized; the launch of HRP is planned for November/December 2013.

Main challenges in the implementation

Fiji is facing the following challenges in the implementation of HRP:

- getting HRP approved by all stakeholders (universities and medical schools);
- lack of human resources – the research unit has only one staff person, and research does not receive enough attention from higher-level policy-makers;
- lack of policies to guide data sharing over public domains;
- non-submission of completed reports at the end of the research (problem with the current manual system);
- lack of IT capacity – a consultant is needed to do the training and to help with further customization as users identify various issues over time, but it is understood that daily work and maintenance of the system will require minimal IT skill; and
- a local IT decree calling for the centralization of all information, communication and technology (ICT) staff in one unit in the government, which may further weaken the support for this system.

**Envisioned next steps**

The next steps in developing the system are envisioned to be:

- get final approval for adopting HRP;
- finalize appropriate SOPs and guidelines (currently in draft);
- strengthen human resource capacity (follow up on a request/proposal for extra personnel); and
- create first metadata reports.

### 2.2.4 The Philippines

**Title:** Philippine National Health Research System

**Presenter:** Ms Merlita Opeña, Philippine Council for Health Research and Development

**Status of the implementation of HRP**

A pilot version of HRP is functional. It is now being piloted by eight of the 126 ethics review committees in the country. Required documents and submission processes are being synchronized, but the system is also being customized to allow some flexibility to individual ethics review committees. A consultation on HRP was organized by the Philippine Health Research Ethics Portal (PHREP) in August 2013. Final customization, testing and training for PHREP will continue until December 2013.

**Status summary:** A pilot version of HRP is under development but still not put to regular use the system is being piloted by several ethics review committees; policy issues are being sorted out.

**Main challenges in the implementation**

The Philippines is facing the following challenges in the implementation of HRP:

- development of a generic system that can cater to the needs of 126 ethics review committees and their diverse review procedures;
- intellectual property protection – concerns about data safety and public transparency (researchers fear that work will be plagiarized when the work is publicly available); and
- guidance for researchers on proposal submission (researchers must choose an ethics review committee to review their proposals).

The following actions were taken to address these challenges:

- system flexibility (inherent within the WHO HRP);
- synchronization and harmonization of required documents and submission processes;
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- clearance duration and notification (modification);
- mandatory use of the system for accreditation of ethics review committees (long-term approach);
- subjection of system administrators to non-disclosure agreements;
- implementation of visibility options in HRP; and
- modification of proposal submission process – proposals are now automatically assigned, instead of offering researchers a choice.

**Envisioned next steps**

The next steps in developing the system are envisioned to be:

- communicate with existing research databases for published research and registries, and align HRP with these databases; and
- continue piloting HRP by several ethics review committees, followed eventually by nationwide implementation.

### 2.2.5 Viet Nam

**Title:** Health research management in Viet Nam

**Presenter:** Mr Le Hieu, Ministry of Health, Viet Nam

**Status of the implementation of HRP**

The HRP is functional but is not yet being used. The plan is to pilot HRP at the Hanoi School of Public Health before making it available to one of the more than 30 research ethics committees in the country.

**Status summary:** The HRP is functional but is not yet being used; it is planned to be piloted at an institutional level (at the Hanoi School of Public Health).

**Main challenges in the implementation**

Viet Nam is facing the following challenges in the implementation of HRP:

- lack of a national regulation or policy for health research;
- separate processes for technical review and ethics review; and
- lack of motivation from researchers and members of research ethics committees. Many are reluctant to use the electronic system and prefer the paper-based system.

**Envisioned next steps**

The next steps in developing the system are envisioned to be:

- encourage the use of IT and the online registry system in health institutions (universities, and research institutions).
• combine and integrate various databases/systems, so to create a single point of access for a research management system;
• harmonize and streamline research review procedures, especially by combining ethical and technical review processes; and
• develop national regulation or policy on health research and provide support for applying IT in research governance, data and information sharing.

2.3 Session 3: Group discussion on key challenges in implementing HRP

A group session was organized to identify key challenges in the implementation of HRP and to discuss what has been done, or could be done, to overcome them.

The challenges that came out of the discussions can be categorized into five broad groups:

(1) Policy and regulatory frameworks: the absence of policy frameworks to steer ethics review committees or other government departments in adopting HRP

(2) Limited capacity for ethics review and approval: limited human and financial resource capacity of ethics review committees

(3) Technical challenges: IT capacity, IT infrastructure and Internet connectivity

(4) Users’ concerns: Users’ concerns about security, confidentiality, transparency and limited IT expertise of researchers/ethics review committees

(5) Ownership and leadership: limited interest from high-level policy-makers in committing resources for governance and management of predominantly externally funded research.

A more extensive overview of the key challenges that came out of the discussions is presented in Annex 3.

2.4 Session 4: IT solutions in improving archiving, access and analysis of research outputs

2.4.1 MongolMed

**Title:** Development of online system for Mongolian scientific literature (MongolMed): process, challenges, benefits and use, sustainability, and way forward

**Presenter:** Dr Burmaajav Badrakh, Ministry of Health, Mongolia

To increase access to health research results from Mongolia, the Mongolian Association of Medical Journals founded MongolMed with the support of the Mongolian Academy of Medical Sciences, the WHO Regional Office for the Western Pacific, and the Mongolian Ministry of Health. MongolMed is an electronic database for archiving and accessing scientific literature published in Mongolian health journals. The bilingual system provides access to articles in English (abstract only) and Mongolian (full-text articles). The key objective of the system was to improve access to and use of health research outputs in Mongolia. MongolMed has helped to increase access to research results for researchers, medical professionals and students, both within the country and abroad.
MongolMed was launched on 30 November 2012. Currently, there are 211 issues of seven medical journals on MongolMed, providing online access to more than 3124 articles published since 1970. MongolMed collects data in a standardized, indexed and searchable format.

The key challenges for MongolMed include convincing publishers to upload articles in more timely fashion, both for existing and newly indexed journals; making further improvements to the system; and improving the visibility of MongolMed to increase utilization.

MongolMed can be accessed at: http://www.mongolmed.mn/.

2.4.2 Health knowledge management in Viet Nam

**Title:** Health knowledge management in Viet Nam: new initiatives with a focus on appropriate technologies and strategies in use of health research results

**Presenter:** Dr Le Van Hoi, Network for Evidence-Informed health policy and management development, Viet Nam

Dr Hoi provided an overview of the status of health knowledge management in Viet Nam. He explained that Viet Nam is facing challenges on five key areas of health knowledge management:

1. Coordinating agency: Viet Nam has a focal department for health knowledge management, namely, the Administration of Science, Technology and Training; however, it no longer has a technical focal point since the closure of the Central Health Information and Technology Institute.

2. Medical journals: Challenges include poor quality of manuscripts, limited peer review, lack of mechanisms to monitor plagiarism and author’s rights, limited IT application, and limited collaboration and technical assistance with external agencies.

3. Health library network: Challenges include lack of standards, weak capacity, poor sharing and availability of information, and absence of a national library of medicine.

4. Network for providing and using evidence: Challenges include lack of capacity, tools and methods to improve practices for using evidence, and limited linkage and collaboration between agencies.

5. Network for developing and applying e-health: This is a new area in Viet Nam which needs development on many aspects.

The presenter made the following suggestions to improve the situation in Viet Nam:

1. Coordinating agency: Establish a centre for health knowledge management under the Administration of Science, Technology and Training in the Ministry of Health.

2. Medical journals: Improve the quality and mainstream international integration of national medical journals in Viet Nam in international medical literature by increasing their access.
(3) Health library network: Improve the technical capacity, linkages and sharing of information resources between medical libraries.

(4) Network for providing and using evidence: Further develop the network for providing and using evidence.

(5) Network for developing and applying e-health: Promote the development of an e-health network.

2.4.3 Developing institutional repositories for health research

**Title**: Developing institutional repositories – a key knowledge management tool: some experiences

**Presenter**: Jeong-Wook Seo, JW Lee Center for Global Medicine, Seoul National University College of Medicine, Republic of Korea

Professor Seo provided an overview of institutional repositories for health knowledge in the Republic of Korea. There are institutional systems for research grants management (and a national system for institutions that do not have their own system) that keep track of information on researchers. There are also institutional ethics review systems that make submission data publicly available.

An online institutional repository for health research at Seoul National University contains 16,000 journal articles published by the university and logs more than 3,000 views every day. One of the reasons for the high number of views is full-text access to articles free of charge. All articles are accessible, even those that have been submitted to and published in a journal.

Open access to health research results is critical. It can be achieved in two possible ways: (1) via open-access journals; and (2) via institutional repositories. The Massachusetts Institute of Technology (MIT) has developed open-source software for institutional repositories that may be adopted by institutions or countries in the Western Pacific Region. Open-access, indexed repositories of health research results can be used to monitor research in a country. Institutional repositories are especially important for countries like Cambodia, the Lao People’s Democratic Republic, Mongolia and Viet Nam. However, none of these countries currently has such a repository. The Seoul National University is attempting to remedy this situation by creating “Lao Space” – an online, bilingual repository for health research in the Lao People’s Democratic Republic.

2.4.4 Microdata repositories

**Title**: Improving archiving and access to health research data: development of online public health microdata repository

**Presenter**: Gaye Parcon, Accelerated Data Program Regional Coordinator for Asia, Manila, Philippines

The Accelerated Data Program (ADP) and the International Household Survey Network (IHSN) have developed open-access software tools for documentation, archiving and dissemination of health research data based on international standards. IHSN is responsible for the development of the tools and guidelines, and ADP helps countries to build statistical capacity. Given the huge
investments associated with health research data collection, there is a need to be able to measure and monitor the use of data better. Several tools are offered, including:

1. Microdata Management Toolkit (specialized metadata editor)
2. National Data Archives (NADA) survey cataloguing system (searchable metadata)
3. Microdata anonymization tools (under development).

ADP and IHSN work in many countries in Africa, Asia, Central America and South America, including all six countries represented at this workshop. They help countries to improve both documentation of microdata (individual record or respondent data) and to improve metadata (often called “data about the data”, i.e. the background or interpretive information). An overview of the benefits, costs and risk of data archiving and open access was presented. A demonstration of microdata repositories from various countries that use NADA tools developed by IHSN and ADP was presented. It was clarified that the software is open source, freely available and can be adapted to accommodate countries’ specific requirements.

2.5 Good practices for health information systems and e-health

Title: International good practices for health information systems and e-health national development

Presenter: Mark Landry, Team Leader, Health Information, Evidence and Research, WHO Regional Office for the Western Pacific, Manila, Philippines

Mr Landry presented the regional approaches to help Member States improve e-health. Regional e-health collaborative communities, such as the Asia eHealth Information Network (AeHIN), which was developed with the input and support of several technical and development partners, is one such approach. AeHIN now has more than 320 partners in 23 countries in the Western Pacific Region. AeHIN is a platform for collaboration and information exchange on e-health. There are various other e-health initiatives that can provide technical support for e-health projects, such as Health Ingenuity Exchange (HingX), the Open Health Information Exchange, and Health Unbound.

2.6 Session 5: Taking it forward: action plan

During this group session, each of the six countries developed an action plan for improving the national system for health research and management, in particular furthering the implementation of HRP.

2.6.1 Lao People’s Democratic Republic

- Advocacy meeting on HRP (December 2013)
- Regulation to adopt HRP by the University of Health Sciences (January 2014)
- Training-of-trainers workshop for faculty members (February 2014)
- Integration of research ethics into undergraduate curriculum (February 2014)
- Training on HRP system for students
2.6.2 Cambodia

- Steps taken toward launching HRP
  - Finalize SOPs of NECHR (December 2013).
  - Final adaptation of HRP (January 2014)
  - Test the system (January/February 2014).
  - Public launching (workshop and mass email communication (February-March 2014)
- Development of a National Health Research Agenda for Cambodia (January-December 2014)
- Introduction of health ICT in public health education (January–April 2014)

2.6.3 Fiji

- Development of HRP (January 2014)
  - SOP endorsement (currently in draft)
  - Re-do stakeholder consultations and workshops after HRP goes live.
  - Research Policy endorsement
  - Project live in Ministry of Health
  - Add the stakeholders in as agreed.
  - Conduct trainings.
- Development of the health data request module
- Support: Ministry of Health and WHO
- Technical support
  - IT support
  - Research management training

2.6.4 Philippines

- Further development of HRP
  - Add on reports.
  - Support institutionalization of HRP for sustainability.
  - Put provisions in the research agreements to improve compliance: uploading and updating of research information will be tied up to release of funding; include obligation to submit microdata and publishable manuscripts.
  - Improve present system to include funder, reviewer (technical, ethical), researcher and research institution’s engagement.
- Expansion and improvement of the Philippine Health Research and Development Information Network (HERDIN) (the national journal article database)
- Study visits, sharing of similar systems
- Capacity-building, technical support (as before)
2.6.5 Viet Nam

- Regulation and policy:
  - Stimulate development of regulation from the Ministry of Health on online research management, including a guideline for institutions on use of HRP (June 2014).
  - Integrate ethical and technical review committee operations (September 2014).

- IT solutions:
  - Develop national HRP (December 2014).
  - Develop institutional research portals (December 2014).

- Capacity-building:
  - Require registration
  - Use research management system.

- Networking in Viet Nam and with other countries

- National workshop on IT solutions for health research governance (March 2014)
  - Request technical support from WHO.
  - Seek financing from the government, donors and others.

2.6.6 Mongolia

- Convene stakeholder meetings (November 2013).
- Meet and select IT companies for designing national HRP (November 2013).
- Design the national HRP (January 2014 – May 2014).
- Train research managers (November 2013).
- Train researchers (February 2014).
- Train members of ethics review committees (March 2014).
- Start registration of research work (from March 2014).
- Revise HRP (May 2014).
- Launch HRP (June 2014).

Technical and financial support from WHO and the Ministry of Health will be needed to achieve these milestones.

2.7 Closing remarks

Dr Bich from the Hanoi School of Public Health closed the workshop. He recognized the importance of the workshop in bringing all participants together to consider the problem of poor health research governance and management. Working together, these countries can improve their national health research systems. Furthermore, Dr Bich thanked the observers from the Hanoi School of Public Health, staff from the WHO Regional Office, and all other participants in making the workshop a useful and productive exercise.
3. CONCLUSIONS AND RECOMMENDATIONS

From the online health research management plans that were presented by the countries, several recommendations that were common to all countries emerged. The following recommendations were suggested as being relevant to all countries.

1. Countries should consider establishing a national health research advisory committee (not just an ethics review committee), with membership from different stakeholders, to provide momentum for improvements to the national health research and management system.

2. Countries should work towards establishing national policies for health research governance (e.g. policies for responsible conduct of health research), where such policies do not exist.

3. Countries should take national ownership of their health research, and be actively involved in assessing what is needed to improve the national health research and management system, and communicate those needs to different partners, including WHO, if external help is needed.

4. Countries should address remaining technical challenges.

In addition, countries should consider additional potential solutions/systems to improve health research management and governance, such as: open-access institutional and/or national repositories for published research articles; microdata repositories, particularly the NADA tool; and local literature databases to improve archiving and access to local, non-English literature (such as HERDIN and MongolMed).

Finally, the workshop recommended that the WHO Regional Office for the Western Pacific should monitor the implementation of the action plans of the six countries that were present at this workshop.

4. ACKNOWLEDGEMENTS

The WHO Regional Office for the Western Pacific would like to thank the Australian Agency for International Development for providing financial support for this workshop.

We acknowledge the Hanoi School of Public Health for administrative and logistic support provided for the workshop.

We also acknowledge the excellent support provided by Dr Roderik Viergever from WHO Headquarters who served as the rapporteur for the workshop. He took comprehensive notes and wrote the first draft of the workshop report.
### AGENDA AND DETAILED PROGRAMME

#### Day 1: Monday, 11 November 2013

<table>
<thead>
<tr>
<th>Time</th>
<th>Title</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>8:00–8:30</td>
<td>Registration</td>
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<tr>
<td>8:30–8:40</td>
<td>Opening remarks</td>
<td>Dr Tran Huu Bich, Vice-Dean, Hanoi School of Public Health Associate Prof. Bui Thi Thu Ha, Dean, HSPH Dr Takeshi Kasai, WHO Representative, Vietnam</td>
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<tr>
<td>8:40–8:50</td>
<td>Welcome</td>
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<td>8:50–9:00</td>
<td>Welcome remarks</td>
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<tr>
<td>9:00–9:10</td>
<td>A round of self-introduction by the participants</td>
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<tr>
<td>9:10–9.30</td>
<td>Group Photo and Coffee Break</td>
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<tr>
<td>9:30–10:15</td>
<td>Issues/challenges in health research systems and potential role of IT solutions in addressing those challenges</td>
<td>Dr Manju Rani, WPRO</td>
</tr>
<tr>
<td>10:15–11:00</td>
<td>Session 1: Setting the scene: How can IT facilitate better and more efficient health research?</td>
<td>Dr Merlita Opena Rapporteur</td>
</tr>
<tr>
<td>10:15–11:00</td>
<td>Adoption of the national health research portal: experience of the Lao People’s Democratic Republic</td>
<td>Lao team</td>
</tr>
<tr>
<td>11:00–11:45</td>
<td>Improving health research governance/management and access to health research outputs in Cambodia: experience, issues and progress made</td>
<td>Cambodia team</td>
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<tr>
<td>11:45–12:30</td>
<td>Reforming health research management in Fiji</td>
<td>Fiji team</td>
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<tr>
<td>12:30 to 13:30</td>
<td>Lunch</td>
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</tbody>
</table>
Session 2: IT applications in improving research governance, oversight: research ethics systems and national health registries (continued)  

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Moderator</th>
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<tbody>
<tr>
<td>13:30–14:15</td>
<td>Philippine National Health Research System</td>
<td>Dr Ir Por</td>
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<tr>
<td>14:15–15:00</td>
<td>Health research management in Viet Nam</td>
<td>Philippines team</td>
</tr>
</tbody>
</table>

15:00-15:15 Coffee break

15:15–16:30 Session 3: Group Work 1 (countries in two groups): key challenges: Political, policy, technical, financial, cultural, infrastructural, regulatory adopt online health research management system and what had been done to overcome them  

Group 1:  
Dr Chanthakhat
Group 2: Dr Pham Cuong

16:30–17:00 Group presentations and conclusions for the day  
Chair person

18:30–20:00 WELCOME RECEPTION

Day 2: Tuesday, 12 November 2013:

Session 4: IT solutions in improving archiving, access and analysis of research outputs  

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Moderator</th>
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<tbody>
<tr>
<td>8.30–9:15</td>
<td>Development of online system for Mongolian scientific literature (MongolMed): process, challenges, benefits and use, sustainability and way forward</td>
<td>Dr Burmaajav Badrakh/Mongolia team</td>
</tr>
<tr>
<td>9:15–10:00</td>
<td>Health knowledge management in Viet Nam: new initiatives with a focus on appropriate technologies and strategies in improving use of research results in development of health system and service</td>
<td>Dr LV Hoi</td>
</tr>
</tbody>
</table>

10:00–10:30 Coffee break

10:30–11:00 Developing institutional repositories—a key knowledge management tool: some experiences  
Dr Jeong-Wook Seo

11:00–11:45 Improving archiving and access to health research data: development of online public health microdata repository  
Ms Gaye Parcon

11:45–12:15 The Asia eHealth Information Network (AeHIN): WPRO support for a collaborative community to develop e-health solutions  
Mr Mark Landry

DISCUSSION

12:15–1:15 Lunch
Session 5: Group Work 2: Taking it forward: action plan

1:15–3:00  Group work 2: Are the potential returns on IT solutions are higher than their costs and will it improves the overall return on research investments? Discussion on timeline, work plan, request for support for implementing online health research management systems and other IT solutions. Each country may develop a workplan with timeline with identification of the areas that require technical support. Country members may work in individual teams.

3:00–3:30  Afternoon Coffee break

Session 6: Recommendations and conclusions

3:30–4:30  Group work Presentation and finalization of country workplans

4:30–5:00  Conclusion
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In the table below, a more detailed description is provided of what the key challenges are to the implementation of the HRP. The challenges are categorized to five broader themes of challenges that followed from the discussions:

- **Policy and regulatory frameworks**: The absence of policy frameworks to steer ERCs in adopting the HRP.
- **Limited capacity for ethics review and approval**: Limited human and financial resource capacity at the ERC.
- **Technical challenges**: IT capacity, IT infrastructure, internet connectivity.
- **User concerns**: User concerns about security, confidentiality, transparency, limited IT expertise of researchers/ethics review.
- **Ownership and leadership**: Limited interest from high-level policymakers in committing resources for this purpose in the context of predominantly externally funded research.

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Explanation of the challenge</th>
<th>What had been or could be done to overcome the challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Policy and regulatory frameworks</strong></td>
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<tr>
<td>Compliance</td>
<td>Compliance of researchers with regard to continuing to update information in the system and upload the research reports after ERC approval was seen as a challenge. In particular external researchers often disappear after they receive ERC approval.</td>
<td>Include a provision in the research agreement regarding uploading and updating of research information. Release research funding in tranches to force people to update research information and upload research reports (only for researchers receiving funding from the country itself).</td>
</tr>
<tr>
<td>Transparency of the review process</td>
<td>Transparency of the review process was viewed as a challenge, particularly with many ERCs in one country.</td>
<td>Implement a standardized review process for all ERCs.</td>
</tr>
<tr>
<td>Disproportionate fees for ethics approval</td>
<td>Fees for research study approval, especially for clinical trials, are sometimes disproportional in some countries. There is a fear for ‘shopping’, that research investigators will try to find the easiest ERC.</td>
<td>Rates for clinical trials review are set by ERCs. Nationally, there should be dialogue or a policy about a reasonable range of fees.</td>
</tr>
<tr>
<td>Challenge</td>
<td>Explanation of the challenge</td>
<td>What had been or could be done to overcome the challenge</td>
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<tr>
<td>No national policy / regulation to steer ethics committees</td>
<td>In some countries, there is no national policy / regulation to encourage and steer ethics committees in adopting an HRP-like system.</td>
<td>Including political bodies in discussions was seen as beneficial to convince policymakers of the importance of creating a national policy / regulation. This results in progress, but it is slow. Also helpful were considered to be: demonstrating successes from other countries; showing that the new policy is aligned with WHO policies; and providing policymakers with meta-data reports to show it is useful.</td>
</tr>
<tr>
<td>No incentive for ERCs to adopt national policy / regulation to steer ethics committees</td>
<td>In some countries, particularly those with many ERCs, there is no incentive for ERCs to adopt HRP system or deliver data to the HRP. Part of the problem is that face-to-face contact with ERCs is difficult in those countries due to the geographical nature of the country.</td>
<td>Health research legislation can make it easier to make ERCs comply with the national policy for ethics approval. In addition, an accreditation system can be considered to help to increase compliance at ERCs.</td>
</tr>
<tr>
<td>Limited capacity for ethics review and approval</td>
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<tr>
<td>Human resource capacity</td>
<td>Several countries noted that human resource capacity for operating the HRP is a problem. It was noted that the system is simple and easy to operate, but that still human resources will be needed to manage the system.</td>
<td>It was noted that a full-time secretariat for managing the HRP system is necessary. Some mentioned that the use of the HRP may actually diminish the work needed to manage ethics review.</td>
</tr>
<tr>
<td>Financial resource capacity</td>
<td>Financial challenges exist to manage the HRP, for example for staff training.</td>
<td>A budget will need to be reserved to manage this system. In developed countries the State offers money for this. However, in many low- and middle-income countries the committees will have to ask fees. Fees based ethics approval can also be a problem (see earlier point on this); some countries recommended to put in place minimum and maximum fees.</td>
</tr>
<tr>
<td><strong>Challenge</strong></td>
<td><strong>Explanation of the challenge</strong></td>
<td><strong>What had been or could be done to overcome the challenge</strong></td>
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</table>
| Human resource capacity              | In the Philippines, there are issues around adequate HR capacity to review proposals. Particular problem is the unequal distribution of these capable researchers across all the different ERC regions and health problems. Another particular problem is that there are very few young researchers who have these capabilities. Part of the problem is that there is no financial incentive to conduct ethics review and acquire training for doing ethics review. | Continuing training on ethics review (formal/non-formal)  
Establish research apprenticeships |

### Technical challenges

<table>
<thead>
<tr>
<th><strong>Institutional – Adopting new systems</strong></th>
<th>The adoption of a new system for ethics approval is accompanied by many technical challenges.</th>
<th>The development of SOPs, policies and training of staff were considered to be beneficial in helping institutions transfer to a new system.</th>
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<td><strong>Research classification</strong></td>
<td>Countries noted that in adopting a new system for research management, due consideration needs to be given to data collection formats and preferences for data classification. In addition, data collection and classification should be harmonized within the country and with other countries, to enable comparability and meta-analysis.</td>
<td>Countries should align themselves in developing a unified approach to classifying data that are collected. The adoption of international standards for data classification are to be preferred.</td>
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<td><strong>Server accessibility</strong></td>
<td>Server for website is not always available in some countries.</td>
<td>A solution is to house the server in a different country.</td>
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<td><strong>Harmonization of Information Systems, Registries, Portals</strong></td>
<td>In the Philippines, which already has a registry for publications and a health research registry, it was felt that there was a danger of not being able to merge the systems.</td>
<td>Development of one Health Research Portal that will be able to link all the systems.</td>
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<td>ERCs with existing information systems</td>
<td>It is difficult to have ERCs that already have IT-systems for ethics approval to adopt the HRP.</td>
<td>2-tier approach:</td>
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<td>1) Those who do not have it will be asked to adopt the HRP system.</td>
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<td>2) Those who already have an IT system for ethics approval will be asked to provide data to the HRP. This can be done through the development of an application programming interface (API) that will allow exchange of information between existing information systems and the new HRP.</td>
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<tr>
<td>Internet access</td>
<td>The availability of internet is limited to bigger cities/municipalities in some countries.</td>
<td>TV wide space technology testing will be tried in the Philippines: if successful will be deployed to all villages.</td>
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<td>User concerns</td>
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<td>Resistance to change</td>
<td>Researchers and reviewers don’t want to use the system. They prefer hard-copy based system.</td>
<td>There will need to be advocacy on the benefits of being transparent. Furthermore, it should be emphasized that transparency in research is seen as an ethical obligation, as is made clear by the Declaration of Helsinki.</td>
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<tr>
<td>Researchers can be reluctant to be transparent</td>
<td>Countries noted that many researchers are reluctant to be transparent about the funding they receive and the research projects that they conduct.</td>
<td>There will need to be advocacy on the benefits of being transparent. Furthermore, it should be emphasized that transparency in research is seen as an ethical obligation, as mandated by the Declaration of Helsinki.</td>
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<td>In addition, the HRP can be customized to countries’ specific requirements. In one country, for example, the HRP was modified to delay public reporting of certain data until researchers felt that such transparency was appropriate.</td>
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| IP Concerns                | Part of the reluctance to be transparent consists of a concern that when data on ongoing research projects are made public, that they may be plagiarized. | Have employees of the ERC sign a non-disclosure agreement.  
Promote transparency of research work to encourage sharing.  
Customize the system in accordance with the ERCs wishes in terms of data transparency. |
| Ownership and leadership   | Support and interest from high-level policymakers is crucial, in particular when there are many ERCs that need to be moved towards adopting an online health research management system in a harmonized way. Unfortunately, policymakers at this level often don’t see the need for these kinds of data. In these countries support for the HRP is lacking at a national level.  
In other countries such support is present, but the country is worried that this may change when there is a change in leadership. | Including political bodies in discussions was seen as beneficial to convince policymakers of the importance of this initiative. This results in progress, but it is slow. Also helpful were considered to be: demonstrating successes from other countries; showing that the new policy is aligned with WHO policies; and providing policymakers with meta-data reports to show it is useful.  
Furthermore, the development of National Ethics Committee guidelines, the enactment of health research laws, and the establishment of Ethics Review Boards may strengthen the country’s health research architecture. These actions were seen as preventing potential problems caused by future leadership change. |