eRegistries
Initiative

learning package

content & software development

core principles

The content & software development learning package aims to provide guidance on the process on how to assist a country in creating an eRegistry, in order to facilitate and pave the way for a successful implementation.

This learning package provides essential information in a step-by-step-approach from the initial mapping of the national guidelines to the final customization and completion of a tailored, electronic system. This learning package is designed for **health care employees from the field of public health, developers, implementers and other related stakeholders**.

The development phase of an eRegistry **requires a comprehensive understanding of the existing situation** with regard to a country's national guidelines, RMNCH interventions and indicators, data collection forms and data elements, reporting requirements, and workflow **in order to create a meaningful database** that follows a logical sequence and is supported by algorithms, validation rules, information icons, and guideline support. The eRegistry approach utilizes RMNCH indicators that are based on the WHO Essential Interventions.

Ongoing communication with users and stakeholders is essential throughout the development process. Careful attention to country customization ensures that the eRegistry adequately captures the local health context. The development process is most effective when approached as an iterative and dynamic dialogue between developers, policy-makers, public health officials, and health care providers. Effective collaboration and communication during this phase will set the stage for long term scalability and sustainability.

step by step guide

This step by step guide provides information on the process of developing the content of an eRegistry. This learning package builds on the work completed in the Needs Assessment and Planning learning package.

STEP I: IDENTIFY, SELECT AND ENGAGE A TEAM

An eRegistry is built on three core elements: an electronic data collection system, uniquely identified and trackable members of the target population, and a health condition of interest. In designing and developing an eRegistry, it is therefore important to identify and engage key stakeholders who work in these domains in your given geographic area of implementation (including national level when building for sustainability and scale), in order to build a system that is truly customized to that area.

Identify key stakeholders that will participate such as members of the core administrative group responsible for facilitating and coordinating the development of the eRegistry. Secondly, identify additional, relevant stakeholders willing to contribute on demand throughout this process.

- Identify the division/department within the health organization of interest (such as Ministry of Health, public health institute, etc) with sustainable growth potential for grounding a core administrative development team

- Engage relevant departments that should be involved such as those working with data collection and management, Information Technology, as well as health policy makers and implementers who can provide input on the workflows of health workers.

- Assist the collaborating country in identifying, selecting and engaging a suitable workforce with the competency to carry out the tasks. Consider if all relevant stakeholders are asked to contribute.

- Establish the core group, and the extended group of stakeholders. Consider contributions of each member.

- Assign responsibility to individuals for further progress.

STEP 2: DEFINE PURPOSE, AIM AND SCOPE FOR THE EREGISTRY

A clear purpose and well defined aims are key to establish a common understanding of the project`s scope and limitations and to be able to communicate the process of developing and running an eRegistry internally and externally.

- Define the primary and secondary purposes of the eRegistry

- Identify the tracked entities, the scope of data collection, and the health cadres involved in data collection

- Determine how to uniquely identify members of the target population, (e.g., use of unique identification numbers or a combination of attributes)

- Clarify initial expectations among the core team, as well as other stakeholders and system users

- Define the cadres of health workers who will be using the various features of the eRegistry, and decide whether this process will involve changes to current guidelines or if the eRegistry will strictly follow current guidelines

- Brainstorm and discuss key issues and areas of concern to be addressed during the development phase.

- Prepare for conducting a development phase

  – Develop a timeline and incorporate contingency plans for unexpected events that incur delays

  – Articulate anticipated problems and discuss how they might be addressed

STEP 3: FORMATIVE RESEARCH PHASE

Gain a clear understanding of the health system to be served by the eRegistry, including the health workers, data they collect, their clinical workflows, and supervisory and reporting systems in order to understand the pain points in the current system, identify opportunities for improvement, and ultimately develop a system that is best suited to their needs and context.

- Prepare and undertake field visits to map clinical work flows, supervisory and reporting demands with the participation of all cadres of health staff who would use the eRegistry.

- Prepare and undertake stakeholder meetings to inform, explore and get feedback

- Verify existing national RMNCH guidelines relevant to the scope of an eRegistry

- Gather existing data collection forms at the point of care

- Identify and document relevant RMNCH interventions at the PHC, district, and national levels

- Map indicators and associated data points for reporting

- Consider if there is a need for revision of guidelines or reporting points; if so, make parallel plans for revision of guidelines and reporting

- Make a prioritization plan for how to improve reporting to match current guidelines with the burden of disease

</> STEP 4: DEVELOPMENT PHASE

Assess the findings from Step 2 and 3, and proceed to begin developing the initial structure of to your eRegistry, including development and refining of requirements for the software development team.

- Get an overview of current clinical guidelines, interventions, indicators and algorithms)

- Based on current guidelines, as well as indicators and data points for reporting, formulate algorithms and data points for electronic tracking

- Define the target groups and to level of complexity of decision support. According to the level of work flow support, create rules for the support and communicate this to software developers in an agreed upon requirements format.

- Enable an iterative review process to ensure that software developers' translation is consistent with health care providers' needs

⚙ STEP 5: CUSTOMIZATION PHASE

This phase is an iterative process of working with stakeholders, software developers, implementers and users and incorporating their feedback to customize the eRegistry software for the specific context.

- Establish a structured and easily accessible digital system for comprehensive and immediate feedback channels among the core working group

- Ensure that content development is in line with the expectations of stakeholders, system users and funders

- Maintain open-minded discussions about translation, use of information buttons, etc., to avoid misinterpretation

- Make sure that there are continuous, parallel processes

that involve and promote information flow among all user groups in the development phases

- Define milestones for developers, implementers and users

- Establish a structured and easily accessible online digital system for comprehensive and detailed feedback from end users

STEP 6: ANALYZE AND SUMMARIZE THE FINDINGS

Summarize findings from the development phase, including strengths, weaknesses, opportunities, and threats.

RESOURCES

- *eRegistries indicators for WHO essential interventions*

- *WHO essential interventions*

- *Principles of Digital Development*

field notes

Ingvild Fjeldheim
Matlab,
Bangladesh
December, 2015

In order to develop a meaningful, and user-friendly electronic record for health care providers, the content and logic has to be carefully customized to fully reflect the existing conditions at the point of care.

The best way to understand real life settings and adequately capture the health context in a certain area or country is through field visits. Field visits provide the unique opportunity to observe firsthand actual working conditions and clinical setting, daily routines, availability of equipment and supplies, provision of health care services and delivery, and, not least, document the workflow, workload and level of health care provided.

Comparing observational information from field visits with actual guidelines provides a much better understanding of the users' challenges and tasks and offers a realistic starting point for developing decision support, options and management plans. Our overall aim is to build a product that is so seamless, elegant, and flexible that users feel confident using it regardless of challenging conditions and circumstances as is very often the case in low-income settings.

field notes

Ingvild Fjeldheim
Gaza,
Palestine
November, 2016

A meaningful electronic record for health care providers should embrace a logical sequence, customized decision support, validation rules, information icons and managment plans.

To accomplish this, it is important to have a comprehensive understanding of the existing guidelines, the RMNCH interventions and indicators and, not at least, the workflow within the focus country or province in order to ensure that the end product adequately captures the national and local health contexts.

During our five year collaboration with Palestine, we have learned that ongoing communication with users and key stakeholders, field visits to health care centers and hospitals, and careful attention to the prospective providers tasks and workflow, are not only essential, but crucial for creating a user-friendly tool. This communication has been most effective when approached as an iterative and dynamic dialogue between the developers, policy-makers, public health officials and health care providers.

The political situation in Palestine and the Gaza strip has significantly affected our ability to arrange important meetings with attendees from both West Bank and Gaza. Thus, to overcome these hurdles, important meetings have been held in Gaza to ensure attendees from both parts of the country.