

THE HRHR INITIATIVE

HARMONIZED REPRODUCTIVE HEALTH REGISTRIES

ISSUE 1 JUNE 2012

GETTING STARTED

We are thrilled to bring you this first newsletter of the hRHR initiative report on progress with this innovative and exciting project.

We have now reached out to include the expertise of a large network, you included, and I am increasingly optimistic that we can develop a practical framework for reproductive health registries to ensure a leap forward in wide scale implementation. Our aim is to help countries overcome the hurdles of ethical and legal

issues, leap-frog the lengthy work of indicator development and harmonization, and serve themselves with free & “ready-to-go” IT solutions for data collection and management. Further, I am happy to see how experts in IT solutions, public health surveillance, statistics and communications collaborate to develop automated solutions for data cleaning, analysis and presentation for various stake-holders – meaning long-term capacity-building can be cut to a

minimum.

In this Newsletter we summarize our scope and present some new advances – please do tell us what you think about the ongoing work! We look forward to bringing you our next update as E-news linked to our new web-site!



Frederik Frøen

PRESENTING HRHR IN BETHLEHEM, MARCH 14-18

The hRHR initiative was represented at the Second International Conference in Gynecology and Obstetrics in the Occupied Palestinian Territory (OPT), in Bethlehem. Frederik Frøen and Victoria Nankabirwa were invited speakers at the conference and used this opportunity to present the initiative for a broad audience of health staff and health ministry from the OPT.

We were also attending a Work Shop in Ramallah where key health players in

the OPT were gathered together to discuss maternity care challenges in their region. We met, among others, our previous colleague from the NIPH, Dr. Bjørn Iversen. Dr. Iversen is stationed in Jerusalem for the next two years as a senior technical advisor at the WHO office, aiming to assist the Ministry of Health (MoH) to establish their first Institute of Public Health.

The MoH is realizing their need to improve the quality of health care for repro-

ductive health (pregnancy, birth, neonatal and postpartum life) nationwide.

The existing data collection in the OPT is suboptimal and in many cases scanty.

As a result of the Ramallah Work Shop, implementation of an efficient, transparent and comprehensive reproductive health registry seems to be strongly supported. The OPT is offered to be a Pilot country for the implementation of the hRHR-framework.

SHARING DOCUMENTS OF HRHR

- *The hRHR-framework initiative is based on transparency— aiming to involve as many contributors and stakeholders as possible.*
- *We invite all recipients of this Newsletter to access and contribute to documents developed in the hRHR. The content of the framework is depending on a broad collaboration.*
- *To get access to our hRHR-Google Docs, please send your Gmail address to infj@fhi.no. If you don't have a Gmail-account, get one here: www.gmail.com*

INSIDE THIS ISSUE:

| | |
|--------------|---|
| ETHICS & LAW | 2 |
| DATASETS | 2 |
| IT-SOLUTIONS | 2 |
| SURVEILLANCE | 3 |
| PILOT SITES | 3 |
| ICD-MM | 3 |
| THAILAND | 4 |

WP I—ETHICAL, LEGAL & SOCIETAL IMPACT



Jane Kaye

Reproductive health includes highly sensitive aspects of human life. Data collections on reproduction must meet high standards to avoid putting mothers, children and care providers at risk of their private data being misused.

The hRHR framework will provide a toolkit to, among others, ensure that the country has; a legal mandate to establish a registry in conformity with existing laws, a governance structure for the

registry to make sure that collection procedures and use (for the purpose of public health and research) are transparent and accountable, procedures and legislation to protect the confidentiality of privacy and the data collected, - and a system to review research carried out on the registry. It is also essential that the implementation of such registries is done in a way that is culturally and socially sensitive with a clear public engagement strategy.

Director and academic lawyer **Jane Kaye** at Oxford University is the leader of this WP

What's new? We are actively seeking partners and experts in law, ethics, politics and the social sciences to build an international network for the development of this toolkit to ensure that what we design is relevant and useful. If you are interested, please contact jane.kaye@law.ox.ac.uk

WP II & III—INDICATORS & DATASETS



Vicki Flenady

Evidence-based guidelines on essential cost-effective interventions to prevent adverse maternal and newborn outcomes must be implemented in maternity care worldwide. There is a need to harmonize collected data with existing guidelines and avoid wasting resources in collecting data with low impact on health improvement. The hRHR framework will provide tools to identify;

relevant priority areas and interventions; best available evidence and adaptation to setting; core indicators needed for health surveillance, monitoring, evaluation of the guidelines. Toolkits will support harmonizing data needs in one universally applicable and harmonized dataset. Director of the Translating Research Into Practice Centre, Mater Medical Research Institute **Vicki**

Flenady is the Leader of this work package.

What's new? Priority interventions based on the existing work of the WHO and The Lancet's stillbirth series have been identified. Indicators for antenatal care are under development. We are seeking PhD students to work with us across the many aspects of these work packages.

WP IV—E-HEALTH & M-HEALTH SOLUTIONS



John Lewis

Today all sorts of data are collected in different ways. Data samples with poor quality are useless in terms of public health surveillance, and research. Effective health monitoring is impossible without harmonization of solutions and management. There are numbers of innovative IT-solutions due to e and m health. The problem is harmonization for optimization of data sharing and cost-effectiveness. This framework will provide sys-

tematic reviews of existing technological solutions on open source platforms and develop a scoring system in terms of core aspects represented in the other WP's; data security, applicability, harmonization for data sharing, user friendliness, abilities in individual tracking from pregnancy through neonatal and postpartum period, harmonization with vital registries and other international standards, ability to provide check-lists,

clinical decision support and reporting systems for health surveillance and monitoring.

Dr. **John Lewis** has extensive empirical experiences and expertise in technology. He will bridge these domains in the hRHR-project.

What's new? Harmonization of various IT solution is a Move towards an integrated open source, e-health architecture for the purpose of optimization of data definition, sharing, analysis and its use.

WP V— HEALTH SURVEILLANCE & FEEDBACK

The primary aim for the hRHR initiative is that no data should be collected unless there are structures and systems developed to provide meaningful use and interpretation. Data should be put to use for systematic surveillance, monitoring, audit and to secure accountability of high quality health care. The hRHR framework will systematically review best practice systems for active surveillance, monitoring, audit and accountability of each guideline hRHR

module – adhering to WHO standards and COIA initiatives. Develop and harmonize data output modules suitable for clinicians, health care managers, and society, regional and international agencies. Develop training modules in WHO's Beyond numbers for ICD MM & ICD PM.

Dr. Victoria Nankabirwa, working at the NIPH is the Leader of this work package; she is a physician from Uganda.

What's new?

Victoria Nankabirwa is working simultaneously with WP V and the ICD-MM. She has been located in Geneva, at the WHO, this May, for the purpose of working more closely with the ICD-MM



Victoria Nankabirwa

WP VI—LEADERSHIP, COORDINATION AND IMPLEMENTATION

hRHR is formally a collaborative initiative between the WHO and the NIPH and is funded by Norad (The Norwegian Agency for Development Cooperation, a specialized directorate under the Ministry of Foreign Affairs).

Most of the technical and coordinating support is provided by The Norwegian Institute of Public Health (NIPH). hRHR can only

reach its potential as a collaborative initiative. To achieve our goals, secure transparency and improve quality we are inviting as many stakeholders as possible to contribute.

The hRHR framework will be ready for implementation by the end of 2012. During 2013 piloting will be performed in numerous sites and countries.

What's new?

Before the "recruitment phase" of the hRHR initiative officially reaches, seven countries are developing pilot plans. These are: the Occupied Palestinian territory (OPT), Uganda, Gambia, Malawi, Burkina Faso, Ethiopia and India. The project group is looking very much forward to the continuation of this rewarding work.



Doris Chou

ICD-MM CAPACITY BUILDING

The fifth millennium development goal seeks to reduce maternal deaths by 75%. This goal cannot be achieved without fairly accurate estimates of maternal deaths and their causes. Unfortunately, many countries are grappling with the attribution of causes of maternal deaths. Currently there is a lot of inconsistency in the attribution and reporting of causes of

death internationally. The International statistical classification of diseases and related health problems, maternal mortality revision (ICD-MM) was established to address this problem. This tool is intended to guide in a standard manner, the collection, coding, tabulation and reporting of maternal mortality statistics. We have been tasked to: 1) Develop a

user friendly application that translates ICD-MM into immediate use, 2) A training tool for ICD-MM and 3) Implement ICD-MM in a couple of countries to improve surveillance for maternal deaths and their causes.

Contact hRHR

HRHR INITIATIVE

Department of International Public Health
Norwegian Institute of Public Health
P.O.Box 4404 Nydalen
N-0403 Oslo, Norway

Phone: +47 21078207
Fax: +47 nn nn nn
E-mail: infj@fhi.no

We are on the web.
[Wwww.fhi.no/hrhr](http://www.fhi.no/hrhr)

HRHR—FACTS

The hRHR initiative is a WHO-owned project aiming to develop and implement a globally harmonized framework for Reproductive Health Registries to support efforts towards Millennium Development Goals 4 and 5.

Norad (The Norwegian Agency for Development Cooperation) is the main financial sponsor of the hRHR initiative.

Project management, technical and coordinating support is provided by the Norwegian Institute of Public Health.

The Department of Reproductive Health and Research at the WHO HQ, Geneva, is the coordinating hub at the WHO.

UP-COMING MEETING WITH MCS IN THAILAND MAY 8-10

The **hRHR**-Project Group will attend the final WHO-meeting for the Multicountry Survey (MCS) on Maternal and Newborn health, in Hua Hin, Thailand, May 8-10th.

There will be 60 people gathered in Hua Hin from the MCS network; employees from the WHO in addition to representatives from all the attending countries in this survey. hRHR is on the

Agenda for the meeting with a presentation and a workshop. The primary objective for the workshop is to get linked up with countries interested in a reproductive health registry and to map their needs regarding this topic.

Secondly we will spend time to sort out in which way we can extract relevant experiences in relation

to IT-systems, guidelines and ELSI-issues/challenges that the MCS-network has experienced along the road.

We are looking forward to attend the MCS-meeting, to the network's final presentation of their main results and, not at least, further options for collaboration.

