**hrHR responds to Women Deliver 2013 call for better data**

“Improved tools for tracking coverage of essential interventions is an important global strategy that will strengthen policies and foster accountability of programmes aimed at women and children,” says Dr. Frederik Frøen, Project Director of the hrHR Initiative. Following the Women Deliver 2013 meeting in Kuala Lumpur, Malaysia, the need for quality data became apparent in order to better understand challenges so that future efforts can pinpoint areas of need and advance the health of women and girls around the world.

With less than 1000 days before the Millennium Development Goals expire, Women Deliver 2013 focused on how MDGs 4 and 5 continue to lag in many countries. **Countdown to 2015** emphasizes the importance of accurate data to effectively manage health systems and ensure accountability. This approach echoes the hrHR Initiative strategy that highlights the need for reproductive registry data that is designed to be routinely communicated to stakeholders including women, health care providers, and public health officials.

**Indicators for better health**

The hrHR Initiative has developed indicators in response to the information needs that arise as countries strive to improve their monitoring of coverage, quality and the effect of the Essential Interventions, Commodities and Guidelines in RMNCH.

“These indicators are specifically developed to monitor quality of care. To date, 216 indicators have been created, however, not all of these indicators are relevant for every country. They can be used as needed,” says Dr. Flenady, Director of Translating Research into Practice at Mater Research in Brisbane, Australia.

The new set of indicators will be subject to international consultations in October and November in Hanoi and Geneva, respectively. See hrHR website for more information.

**Palestine poised to be a pioneer in hrHR**

“Palestine will be the first country to assess their current mother-child data using the hrHR Needs Assessment tool,” says Dr. Bjørn Iversen, Senior Technical Advisor, WHO Palestine. The hrHR Initiative has developed a Needs Assessment Tool to identify existing capacity and gaps in the public health surveillance system, specifically concerning reproductive health.

By focusing on high quality reproductive, maternal, newborn, and child health (RMNCH) data across the continuum of care, the hrHR Initiative will help countries to assess how data can improve health outcomes.

**Meeting with the Norwegian Minister of Health**

A delegation of Palestinian health officials came to Norway in May 2013 to promote collaboration between the Norwegian Institute of Public Health (NIPH) and the newly established Palestinian National Institute of Public Health (PNIPH). One of their top priorities is to improve capacity building projects and develop further research collaborations in Palestine.

Dr. Hani Abdeen (Palestinian Minister of Health), Dr. Assad Ramlawi (Palestinian Director General of Primary Health Care and Public Health) and Dr. Mahmoud Daher (WHO Country Head) met with Jonas Gahr Støre (Norwegian Minister of Health), to discuss health priorities. Støre commented that Palestine needs to increase their focus on primary health care prevention and strengthen the development of their new public health institute.

Meeting with the delegation, Dr. Frøen presented the hrHR Initiative. Also present were Gry Larsen (Deputy Minister of Foreign Affairs), Yasser al Najjar (Palestinian Ambassador to Norway), Anne Bergh (NIPH International Director) and Dr. Camilla Stoltenberg (NIPH Director General). The Palestinian delegation will continue their collaborating effort under the direction of the newly appointed Minister of Health, Dr. Jawad Awwad.
ELSI Checklist fundamental in creating reproductive health registries

A checklist on ethical issues forms the foundation for creating Reproductive Health Registries,” says Dr. Jane Kaye, who leads the activities in Work Package 1 of the harmonized Reproductive Health Registries Initiative (hRHR) at the University of Oxford. Her work covers the ethical, legal, and societal implications (ELSI) of developing a reproductive health registry. Dr. Kaye notes that “for this work package, we sought to identify key legal features that need to be considered when establishing a reproductive health registry.” She adds that the ELSI checklist’s focus on legal and ethical issues “will ensure that the privacy and confidentiality of all reproductive health data is maintained at the highest level.” Dr. Kaye emphasized that integrating data protection with existing governance structures and legal mandates also underscores an important feature of the checklist.

A member of Dr. Kaye’s team, Andelka Phillips incorporated their initial work on reviews of existing governance structures in six countries—Australia, Ghana, India, Norway, the UK and Palestine as an initial pilot. She specified that other countries have been included to provide more perspectives. “We have expanded our collaboration with colleagues in various jurisdictions, particularly mHealth Alliance, and are comparing these initial results with legal analysis of information law in other jurisdictions (Bangladesh, Chile, Nigeria, Peru, Tanzania and Uganda),” she explained.

Conflicting rules among countries

“Our work identifies the need for data protection and harmonization because even in high income countries, there are conflicting data protection laws,” says Dr. Kaye. In the Guardian recently, Angela Merkel, Chancellor of Germany urged for tougher EU data protection laws because there were differences within Europe. She argued that while Germany has “very good data protection law,” Britain has “a very different philosophy” about data protection. However, the UK justice minister Lord McNally, said “we do not believe the current European Union proposals strike the right balance. We are negotiating for EU legislation that contains less prescription and cost burdens while providing greater flexibility for member states to tailor legislation according to national tradition and practice.” The call from European leaders demonstrates the critical need for data protection and harmonization which Kaye notes is a key component of hRHR.

hRHR data collections using e and mHealth

Although data collection is often considered to be an additional burden to healthcare, the hRHR Initiative aims to develop e and mHealth tools to help health workers report and integrate data collection in patient management tools. “Our goal is that the hRHR Initiative will provide countries with clear guidance in selecting the right tools for data collection,” says Dr. John Lewis, ICT work package leader for the hRHR Initiative. He maintains that countries can use free and open source systems to collect and store their data. “Our systematic reviews demonstrate that there are many free, reliable solutions which make investments in commercial software unnecessary.”

Better data collection and management

With the continuous changes in information and communications technology globally, the demand for better data collection technology has increased with an aim to improve data quality, management and real time availability to stakeholders. “Several e and mHealth systems are already deployed in numerous locations by various national and international agencies, commercial and nonprofit organizations with limited focus on data sharing, privacy, feedback, quality checks, clinical support decisions, linkage between e and mHealth solution, and the use of source software development,” adds Dr. Lewis.

Among the most widely distributed software is DHIS 2.0 with a registry module tracker that was developed by the Health Information Systems Programme (HISP) - a global network established and coordinated by the Department of Informatics at the University of Oslo. Based on the current ICT context, Dr. Lewis argues that “hRHR addresses these challenges through an e and mHealth work package that aims to provide tools based on existing technological solutions, using free and open source platforms.”

Harmonization with international standards

Working with the World Health Organization on the Reproductive Health Registries (RHR) framework, Dr. Lewis is developing a scoring system to assess core aspects of RHR. “We are collaborating with open source software providers and we strive for applicability to different settings; harmonization with other international standards for data sharing and collaboration and user friendliness for all stakeholders,” says Dr. Lewis.

Upcoming event:

The hRHR International Workshop will predece the International Stillbirth Alliance (ISA) Annual Conference
Hanoi, Vietnam — October 14-16, 2013

The hRHR team of experts will meet for consultations on ethics, law, indicators, data sets, e and mHealth solutions, and the use of tools being developed in the hRHR Initiative.

“We are delighted that the hRHR Initiative has chosen to convene before the ISA Conference. The 2011 Lancet series on stillbirth prevention highlighted the need for better data on pregnancies and stillbirths and the hRHR work will contribute to our common goal to prevent stillbirth across the globe.”
- Prof. David Ellwood
Chair of the International Stillbirth Alliance

“hRHR will present the new recommended indicators for all essential interventions for women and children. We are looking forward to a fruitful discussion and collaboration with the International Stillbirth Alliance.”
- Vicki Flenday, PhD.
Member hRHR steering group, Mater Medical Research Institute, Brisbane, Australia

For more information please visit our website: www.fhi.no/hRHR or contact

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