





Prince Mahidol Award Conference

Jobal Health Information Forum Prince Mahidol Award Conference 27 – 30 January 2010 Bangkok, Thailand



Prince Mahidol Award Conference

Prince Mahidol Award

Prince Mahidol Award was established in 1992, to commemorate the 100th birthday anniversary of Prince Mahidol of Songkla who is recognized by the Thais as *'The Father of Modern Medicine and Public Health of Thailand'.*

His Royal Highness Prince Mahidol of Songkla was born on January 1, 1892, a royal son of Their Majesties King Rama V and Queen Savang Vadhana of Siam. He received his education in England and Germany and earned a commission as a lieutenant in the Imperial German Navy in 1912. In that same year, His Majesty King Rama VI also commissioned him as a lieutenant in the Royal Thai Navy.

Prince Mahidol of Songkla had noted, while serving in the Royal Thai Navy, the serious need for improvement in the standards of medical practitioners and public health in Thailand. In undertaking such mission, he decided to study public health at M.I.T. and medicine at Harvard University, U.S.A. Prince Mahidol set in motion a whole range of activities in accordance with his conviction that human resources development at the national level was of utmost importance and his belief that improvement of public health constituted an essential factor in national development. During the first period of his residence at Harvard, Prince Mahidol negotiated and concluded, on behalf of the Royal Thai Government, an agreement with the Rockefeller Foundation on assistance for medical and nursing education in Thailand. One of his primary tasks was to lay a solid foundation for teaching basic sciences which Prince Mahidol pursued through all necessary measures. These included the provision of a considerable sum of his own money as scholarships for talented students to study abroad.

After he returned home with his well-earned M.D. and C.P.H. in 1928 Prince Mahidol taught preventive and social medicine to final year medical students at Siriraj Medical School. He also worked as a resident doctor at McCormick Hospital in Chiang Mai and performed operations alongside Dr. E.C. Cord, Director of the hospital. As ever, Prince Mahidol did much more than was required in attending his patients, taking care of needy patients at all hours of the day and night, and even, according to records, donating his own blood for them.

Prince Mahidol's initiatives and efforts produced a most remarkable and lasting impact on the advancement of modern medicine and public health in Thailand such that he was subsequently honoured with the title of *"Father of Modern Medicine and Public Health of Thailand".*

In commemoration of the Centenary of the Birthday of His Royal Highness Prince Mahidol of Songkla on Janurary 1, 1992, the Prince Mahidol Award Foundation was established under the Royal Patronage of His Majesty the King Bhumibol Adulyadej to bestow international awards upon individuals or institutions which have made outstanding and exemplary contributions to the advancement of medical, and public health and human services in the world.

The Prince Mahidol Award will be conferred on an annual basis with prizes worth a total of approximately USD 100,000. A Committee, consisting of world-renowned scientists and public health experts, will recommend the selection of awardees whose nominations should be submitted to the Secretary-General of the Foundation before May 31st of each year. The committee will also decide on the number of prizes to be awarded annually, which shall not exceed two in any one year. The prizes will be given to outstanding performance and/ or research in the field of medicine for the benefit of mankind and for outstanding contribution in the field of public health for the sake of the well-being of the people. These two categories were established in commemoration of His Royal Highness Prince Mahidol's graduation with Doctor of Medicine (Cum Laude) and Certificate of Public Health and in respect to his speech that:

"True success is not in the learning, but in its application to the benefit of mankind".

The Prince Mahidol Award ceremony will be held in Bangkok in January each year and presided over by His Majesty the King of Thailand.

MESSAGE FROM THE CHAIRS OF THE INTERNATIONAL ORGANIZING COMMITTEE

Global efforts to achieve the Millennium Development Goals (MDGs) by 2015, combined with resolutions to enhance the impact and sustainability of development aid, have placed the health systems of developing countries under increasing scrutiny. A strong, integrated health information system is the cornerstone of an optimal health system, vital for the collection of data and generation of information necessary for health and development workers at all levels to make best use of the finite resources available to them.

Getting the right information, at the right time, into the hands of doctors and nurses in towns and villages, and officials and policy makers in Ministries of Health and international development agencies enables them to make informed decisions and account for their actions and expenditures. In fact, where public health is concerned, the difference between good decisions and poor decisions can mean the difference between life and death.

While the lack of reliable information on the causes of sickness and death presents a major obstacle for governments intent on improving the health of their people, establishing and maintaining a successful health information system is far from simple. It requires steady and long-term commitment and investment from a network of partners, working towards a common goal. Yet despite the challenges, success stories are emerging around the world and there are many lessons and best practices to be shared with other countries that decide to embark along the same path.

This year, the Prince Mahidol Award Conference has joined forces with international partners including the Health Metrics Network, the World Health Organization, the World Bank, and the Rockefeller Foundation to host the Global Forum on Health Information to highlight the achievements and challenges to date. This conference follows commitments made at the G8 meeting in July 2008 on Health Systems Strengthening, which created a strong impetus to enhance health information systems in developing countries.

As Chairs of the Organizing Committee, we are delighted to welcome you to Bangkok, to join more than 400 fellow information experts and champions from within and beyond the health sector. We encourage your lively participation and debate to help shape and deliver the following desired outcomes of the conference:

- 1. To promote a shared understanding of the value of strong health information systems for MDG reporting, emergency preparedness and response and to transform the performance of health systems.
- 2. To identify and better understand gaps in the development of health information systems and evaluate specific opportunities to enhance their performance.
- 3. To agree a priority agenda of action for strengthening health information systems, drawing on a broader and stronger collaboration among diverse stakeholders.

Highlights of the next few days include demonstration of the value of strong health information systems, the role of health information in pandemic preparedness and response and spotlights on key players responsible for improving health information for health-related goals. We hope you will also take the opportunity to attend the special side meetings, Marketplace events and also site visits, where you will be able to witness Thailand's health information systems first-hand.

We would like to thank the many individuals and organizations that have come together to make this conference a success, in particular the international partners, the Prince Mahidol Award Foundation and the Royal Thai Government. We would also like to express our thanks to the Secretariat Team that has worked so hard over many months to plan and prepare for the conference.

We wish you all a stimulating week and hope that you will leave Bangkok with renewed energy and enthusiasm to work together to achieve our shared goal of better information, better decisions and better health for all.

Sam K. Stenfice Vicharn Panich. Gi Errors

DR. SALLY STANSFIELD

DR. VICHARN PANICH

DR. TIM EVANS

CHAIRPERSONS CONFERENCE ORGANIZING COMMITTEE

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CONFERENCE SPONSORS

445

SIDE MEETINGS

Tuesday, 26 January 2010		
08.30-13.00	Building Capacity for civil registration and vital statistics: strategies and tools by HMN, WHO, University of Queensland	Lotus Suite 1, 22 nd Fl.
08.30-11.30	Health System Funding Platform Consultation by GAVI, World Bank and GFATM	Lotus Suite 11, 22 nd Fl.
09.00-12.00	Universal Coverage – What else do we need apart from obtaining and analyzing information? by WHO and IHPP	Lotus Suite 9, 22 nd Fl.
09.00-17.00	Enterprise Architecture for Integrated Health Information Systems (Technical Briefing) by Jembi Health Systems	Lotus Suite 12, 22 nd FI.
09.00-17.00	Exploring technical partnerships for better disease, detection and rapid response by Google	Lotus Suite 8, 22 nd Fl.
10.30-12.00	The Vital Role of Government Ownership and Managemen of Health Data and Information Systems as a National Asset by USAID	Lotus Suite 5, 22 nd Fl.
11.30-18.00	HMN Board Meeting by HMN	Lotus Suite 3, 22 nd FI.
13.00-15.30	Making Results Based Management Work: The Institutional Imperative by USAID	Lotus Suite 5, 22 nd Fl.
13.00-17.30	Increasing the policy relevance of health expenditure information by WHO, World Bank and IHPP	Lotus Suite 9, 22 nd Fl.
13.30-17.30	The Routine Health Information Network (RHINO): New Approaches for Strengthening Routine Health Information Systems (RHIS) by RHINO	Lotus Suite 7, 22 nd Fl.
17.30-19.30	Thailand Health Financing : Achievement and Challenges by World Bank	World Ballroom C, 23 rd Floor
Friday, 29 January 2010		
07.30-09.00	Side Meeting of the Hyderabad Meeting by Results for Development	Lotus Suite 8, 22 nd Fl.

CONFERENCE PROGRAM IN BRIEF

Wednesday, 27 January 2010		
07.00-17.00	Optional Field Trip	
	Thursday, 28 January 2010	
09.00-09.10	Open Ceremony by Her Royal Highness Princess Maha Chakri Sirindhorn	Convention Center A2, 22 nd Fl.
09.10-09.50	Keynote Speech	
09.50-11.00	Break	Convention Center B2, 22 nd Fl.
11.00-12.30	Plenary Session 1 Health Information Systems : the case , their value, the current and the future challenges	Convention Center A2, 22 nd Fl.
12.30-14.00	Lunch	Convention Center B2, 22 nd Fl.
14.00-16.30 (Break during 14.30-15.00)	Parallel Session 1.1 Renewing policy and legislation for health information	Lotus Suite 1 & 2, 22 nd Fl.
	Parallel Session 1.2 Tracking and communicating public health emergencies from the front lines	Lotus Suite 3 & 4, 22 nd Fl.
	Parallel Session 1.3 Informing the response to chronic diseases	Lotus Suite 5 & 6, 22 nd Fl.
	Parallel Session 1.4 Generating global evidence : births, deaths and causes of death	Lotus Suite 7, 22 nd Fl.
	Parallel Session 1.5 Choosing and using standards for interoperable information systems	Lotus Suite 10, 22 nd FI.
17.30-18.00	Cocktail Reception	World Ballroom, 23rd Fl.
18.00-20.30	Welcome Dinner hosted by Royal Thai Government	World Ballroom A-C, 23 rd Fl.
	Special presentation by Hans Rosling	

CONFERENCE PROGRAM IN BRIEF

Friday, 29 January 2010			
09.00-10.00	Plenary Session 2 Stepping up to the plate: who does what to improve health information for monitoring health-related goals?	Convention Center A2, 22 nd FI.	
10.00-10.30	Break	Convention Center B2, 22 nd Fl.	
10.30-12.30	Parallel Session 2.1 Tracking country health systems performance	Lotus Suite 1 & 2, 22 nd Fl.	
	Parallel Session 2.2 Financial and human resources for HIS	Lotus Suite 3 & 4, 22 nd Fl.	
	Parallel Session 2.3 Universal access to health and health services: Essential information to track progress and support management. From measuring inputs to measuring impact?	Lotus Suite 5 & 6, 22 nd FI.	
	Parallel Session 2.4 Public stewardship of private providers : the role of health information systems	Lotus Suite 7, 22 nd Fl.	
12.30-13.30	Lunch	Convention Center B2, 22 nd Fl.	
13.30-14.30	Plenary Session 3 Enhancing global health secutiry : Information sysems as the foundation of effective pandemic preparedness and response	Convention Center A2, 22 nd FI.	
14.30-15.00	Break	Convention Center B2, 22 nd Fl.	
15.00-17.00	Parallel Session 3.1 Improving transparency through collaboration across sectors	Lotus Suite 1&2, 22 nd Fl.	
	Parallel Session 3.2 <i>Exploring the frontiers of health information</i> <i>in a petabyte age</i>	Lotus Suite 3 & 4, 22 nd FI.	
	Parallel Session 3.3 Measuring the un-measurable: Death, disease, health and happiness	Lotus Suite 5 & 6, 22 nd Fl.	
	Parallel Session 3.4 Harmonizing multiple health information systems through effective system analysis and design	Lotus Suite 10, 22 nd FI.	
	Parallel Session 3.5 Managing complex data in health crises : Challenges for national health information systems	Lotus Suite 7, 22 nd Fl.	
17.00-19.00	Call to Action Finalization Session	Lotus Suite 11, 22 nd Fl.	

CONFERENCE PROGRAM IN BRIEF

Saturday, 30 January 2010		
09.00-10.30	Conference Synthesis Session Summary, Conclusion and Policy Recommendations	World Ballroom A-C, 23 rd Fl.
10.30-11.00	Break	World Ballroom Foyer, 23 rd Fl.
11.00-12.00	Call to Action Closing Ceremony	World Ballroom A-C, 23 rd Fl.
12.00-13.00	Lunch	Delegate Bar, 23rd Fl.
13.30-16.30	International Organizing Committee Meeting	Lotus Suite 7, 22 nd Fl.

LIST OF SPEAKERS, PANELISTS, MODERATORS, CHAIRS AND RAPPORTEURS

Speaker / Panelist	Moderator / Chair	Rapporteur
Keynote Session		
Anne Mills Keizo Takemi		Hannah Cooper Nanoot Maturapote Jessica Schull Sirinart Tongsiri
Plenary Session 1: Health Information	Systems: the case, their value, the	e current and the future challenges
Ariel Pablos-Mendez Julian Schweitzer Sally Stansfield Jeanette Vega	Richard Horton	Hannah Cooper Michael St. Louis Vasoontara Yieng
Parallel Session 1.1: Renewing pol	icy and legislation for health in	formation
Karl Brown Maria Graciela Gamarra de Caceres Michael Graven Roger Magnusson Eric Rasmussen	Sally Stansfield	Christoph Bunge Tisha Gerber Tipicha Posayanonda Thaksaphon Thamarangsi
Parallel Session 1.2: Tracking and	communicating public health e	mergencies from the front lines
David Aylward John S. Brownstein Ta-Chien Chan Channe Suy Ieng Vanra Prapas Weerapol	Mark Smolinski	Surasak Chaisong Peerapond Chutisuntarakul Sherrilynne Fuller Julie Pavlin
Parallel Session 1.3: Informing the	response to chronic diseases	
Wichai Aekplakorn Christopher Bailey Rajesh Kumar	Rafael Lozano	John Cutler Supawan Manosoontorn Chanin Sakul-isriyaporn
Parallel Session 1.4: Generating gl	obal evidence: births, deaths a	nd causes of death
Alan Lopez Prasanta Mahapatra Joyce W. Mugo Sam Notzon Peter Kim Streatfield	Armin Fidler	Carla Abou-Zahr Kanitta Bundhamcharoen Lene Mikkelsen Vasoontara Yieng
Parallel Session 1.5: Choosing and	l using standards for interopera	ble information systems
Beatriz de Faria Leao Andrew Grant William Hammond Patrick Whitaker Jennifer Zelmer	William Hammond	Boonchai Kijsanayotin Ramesh Krishnamurthy Jessica Shull Chanwit Tribuddharat

LIST OF SPEAKERS, PANELISTS, MODERATORS, CHAIRS AND RAPPORTEURS

Speaker / Panelist	Moderator / Chair	Rapporteur	
Plenary Session 2: Stepping up to the plate: who does what to improve health information for monitoring health-related goals?			
Ties Boerma Mark Landry Daniel Low-Beer Sania Nishtar Frank Nyonator	Timothy Evans	Kanitta Bundhamcharoen Hannah Cooper Elizabeth Peloso Sombat Thanprasertsuks	
Parallel Session 2.1: Tracking cou	ntry health systems performand	ce	
Tea Collins Candy Day Sania Nishtar Phusit Prakongsai Christopher Simoonga	Daniel Low-Beer	Christopher Bailey Laragh Gollogly Weerasak Putthasri Thaworn Sakunphanit	
Parallel Session 2.2: Financial and human resources for HIS			
Charu Garg Magnus Gborie Brad Herbert William Hersh Alvin Marcelo Maurice Mars	Keizo Takemi	Christoph Bunge Walaiporn Patcharanarumol Jadej Thammatach-Aree	
Parallel Session 2.3: Universal access to health and health services: Essential information to track progress and support management. From measuring inputs to measuring impact?			
Hannes Danilov Supon Limwattananon J. Rachel Lu Giota Panopoulou Adam Wagstaff	Adam Wagstaff	Mark Amexo Sutayut Osornprasop Pongsadhorn Pokpermdee Aparnaa Somanathan	
Parallel Session 2.4: Public stewardship of private providers: The role of health information systems			
Richard Coker Phal Des Krishnamurthy (Gopi) Gopalakrishnar Fola Laoye	David de Ferranti Frank Rijsberman	Lily Dorment Natalie Phaholyothin Pen Suwannarat	

LIST OF SPEAKERS, PANELISTS, MODERATORS, CHAIRS AND RAPPORTEURS

Speaker / Panelist	Moderator / Chair	Rapporteur		
Plenary Session 3: Enhancing global health security: Information systems as the foundation of effective pandemic preparedness and response				
Richard Cash Bounlay Phommasack Guenel Rodier	Miriam Were	Surasak Chaisong Martin Field Eric Rassmusen Thaksaphon Thamarangsi		
Parallel Session 3.1: Improving tr	Parallel Session 3.1: Improving transparency through collaboration across sectors			
Mohamed-El-Heyba Berrou Alan Lopez Jasap Dam Nagari-Popoitai Ivo Njosa	Richard Manning	Tisha Gerber Kathryn Graczyk Nanoot Maturapote Weranuch Wongwatanakul		
Parallel Session 3.2: Exploring th	e frontiers of health information	in a petabyte age		
Mridul Chowdhury James DelloStritto M. Chris Gibbons Gabe Rijpma Julia Royall	Renata Bushko	Peerapond Chutisuntarakul Martin Field Natalie Phaholyothin Steven Uggowitzer		
Parallel Session 3.3: Measuring the un-measurable: Death, disease, health and happiness				
Ronald Colman Timothy Evans Apirak Kosayodhin Dorji Penjore	Laragh Gollogly	Christoph Bunge Frances Rice Sirinart Tongsiri		
Parallel Session 3.4: Harmonizing multiple health information systems through effective system analysis and design				
Michael Bainbridge Ngai-Tseung Cheung Richard Gakuba David Lubinski Ron Parker David Ross Christopher Seebregts	David Ross	Elizabeth Peloso Bordin Sapsomboon Jessica Shull Iyarit Thaipisuttikul		
Parallel Session 3.5: Managing complex data in health crises: Challenges for national health information systems				
Keith Doyle Mica Endsley Juan Eugenio Hernández Avilá Tsehaynesh Messele Augusto Pinto	Michael St. Louis	Mark Amexo Ramesh Krishnamurthy Pongsadhorn Pokpermdee Tipicha Posayanonda		
Conference Synthesis Session: S	ummary, Conclusion and Policy	Recommendations		
		Pinii Faramnuayohol		

Pinij Faramnuayphol Jeff Johns Toomas Palu Viroj Tangchareonsathien

PRINCE MAHIDOL AWARD CONFERENCE 2010

GLOBAL HEALTH INFORMATION FORUM

In 2010 a 'Call to Action' on Health Information System (HIS) will be launched to fully support and recognize that HIS strengthening is critical to improving global health. To ensure effective coordination, the Health Metrics Network, the Prince Mahidol Award Conference, with support of the World Health Organization, the World Bank, the Rockefeller Foundation and other partners, will hold the Global Health Information Forum dedicated to bringing stakeholders together and providing a platform for a renewed energy and commitment to investing in and building the capacities of health information systems.

BACKGROUND

Accurate information provides a foundation for sound decisionmaking. Where public health is concerned, the difference between good decisions and poor decisions can mean the difference between life and death. The lack of reliable information on the causes of sickness and death is a major obstacle for any attempt to improve the health of people in developing countries. Health information is essential to track the health needs of populations, to guide the design and implementation of health programmes, and to assess what works and what does not.

To set up and maintain a successful health-information system is a considerable task, requiring a network of partners, working towards a common goal. Several partners including the Health Metrics Network, the World Health Organization, the World Bank, the Rockefeller Foundation and the Prince Mahidol Award Conference will hold the first Global Conference on Health Information Systems. This conference is in line with the commitment by the G8 meeting in July 2008 on Health Systems Strengthening which focuses on Health Information Systems, Human Resources for Health and Health Care Financing. This commitment had produced a strong impetus to the movement to further strengthen HIS.

GLOBAL HIS FORUM OBJECTIVES

Four core objectives are proposed:

1. Firmly position HIS as a strategic driver of health systems strengthening and performance management of broader development outcomes.

- Highlight the benefits of strong HIS and their potential role in transforming the effectiveness of health systems and the performance of multisectoral development outcomes.
- Raise awareness of past neglect of this area of health and the consequences, especially in developing countries (e.g. Reporting burden on countries, national variances in attitudes towards HIS, lack of technical consistency, lack of ways to share best practices, impact on allocation of results-based global health funds).
- Highlight the importance of HIS to manage performance, monitor and evaluate progress towards the MDGs (reference to MDG reporting in 2010), and monitor the effectiveness of donor health funding.

2. Broaden and unite the constituency of potential allies behind a shared vision and action plan for HIS strengthening.

- Broaden the diversity and interaction of groups engaged in HIS: health, finance, information technology, civil society, and others.
- Raise visibility of the cause and the breadth of engagement to a higher level.
- Inspire broad social movement necessary to achieve progress in HIS.
- Identify ways for different partners to work together and contribute their unique strengths towards a common goal.
- Promote key HMN values: partnership, country leadership, transparency, coherence, sustainability, empowering.

3. Showcase HIS progress and capacity-building in developing countries.

- Outline critical elements for success: political leadership and champions; technological leadership and innovation; expert consensus around the approach; management that effectively uses the information; sufficient financial resources.
- Highlight the HMN Framework and strategy, and the catalytic role of HMN in improving HIS.

- Highlight key investments and results to date.
- Highlight the major challenges, gaps and common ground for future progress.
- Announce awards for major HIS successes and champions.
- 4. Secure high-level commitment to drive future action.
- Highlight relevant commitments and endorsements to date (e.g. WHA endorsement of the HMN Framework in 2007).
- Create a shared understanding of the potential of HIS.
- Public declaration of support for HIS through a 'Call to Action'.

OUTCOMES

- Ensure HIS has prominent place on health and development agendas.
- Capacity of the HMN Network goes to scale.
- Recognition for HMN's enabling role, and progress to date in individual countries.
- Broad understanding among stakeholders of the potential of HIS to improve the effectiveness of public health expenditure and actions.
- High-level 'Call to Action' of commitment to HIS and proposed path forward.
- Outcome document reporting accomplishments of the Forum, follow-up actions, and a Marketplace publication of emerging good practice in HIS.

PARTICIPANTS

- Approximately 400-500 participants who are high-level stakeholders representing the existing and potential HIS landscape, including both demand and supply sides of HIS from developing countries and developed countries from every region will be invited.
- Potential participants are ministers, senior government officials, intergovernmental organizations, international development partners, Global Health Initiatives, health policy and health systems researchers and advocators, statisticians, information technology experts and civil society organisations.

FIELD TRIP PROGRAM

Wednesday 27 January 2010 Field Trips Sites:

- 1. Saraburi Regional Hospital HIS in rural health infrastructures
- 2. Bumrungrad International Hospital/Bangkok Hospital IT for hospital management and medical tourism
- 3. Ang Thong Provincial Health Office HIS for provincial health management
- 4. Ratchaburi Provincial Health Office HIS for provincial health management
- 5. National Health Security Office/SSO HIS for Universal Health Coverage
- 6. Bureau of Registration Administration and Bureau of Health Policy and Strategy
- 7. Siriraj Hospital IT in medical school and Thai Traditional Medicine

Thursday 28 January 2010

9.00 – 9.10 Opening Ceremony Her Royal Highness Princess Maha Chakri Sirindhorn

9.10 – 9.50 Prince Mahidol Award VDO presentation (10 min)

Keynote Speeches

Anne Mills, Prince Mahidol Award Laureate 2009, Head of Department of Public Health and Policy, London School of Hygiene and Tropical Medicine, University of London

Keizo Takemi, Research Fellow; Professor, Japan Center for International Exchange; Tokai University and former Senior Vice Minister of Health, Labour and Welfare, Japan

9.50 – 11.00 Coffee Break

11.00 – 12.30Plenary Session 1Health Information Systems: the case, their value, the current and future challenges

VDO presentation (10 min)

Moderator: Richard Horton, Editor-in-Chief, The Lancet

Panelists:

- 1. Sally Stansfield, Executive Secretary, Health Metrics Network
- 2. Ariel Pablos-Mendez, Managing Director, Rockefeller Foundation
- 3. Jeanette Vega, Viceminister, Ministry of Health, Chile
- 4. Julian Schweitzer, Acting Vice President, The World Bank

12.30 – 14.00 Lunch

Thursday 28 January 2010

14.00 – 16.30 (Coffee Break included)

Parallel Session 1.1

Renewing policy and legislation for health information

Moderator: Sally Stansfield, Executive Secretary, Health Metrics Network

- Health IT in developing countries: legal, ethical and governance priorities
 Roger Magnusson, Professor of Health Law and Governance, Faculty of Law, University of Sydney,
- 2. Policy and Technology in Health Information Systems Eric Rasmussen, CEO, InSTEDD
- Implementing, national one patient one record integrated comprehensive system in Belize Michael Graven, Senior Advisor of Health Affairs, Government of Belize
- Democratization of information within the health reform framework – Paraguay's national health information system – SINAS Maria Graciela Gamarra de Caceres, General Director of Strategic Information of Health, Ministry of Health, Paraguay
- Revisiting health information and eHealth policies and governance structures in an increasingly complex environment Karl Brown, Associate Director of Applied Technology, The Rockefeller Foundation

Thursday 28 January 2010

14.00 – 16.30 (Coffee Break included)

Parallel Session 1.2

Tracking and communicating public health emergencies from the front lines

Moderator: Mark Smolinski, Director, Global Health, Google.org

Speakers:

- Improving on the past leng Vanra, IT Consultant, WHO/CDCMOH, Cambodia Channe Suy, Product Manager, InSTEDD (iLAB), Cambodia
- Realities of the present
 Prapas Weerapol, Mukdahan MBDS Associate
 Province Coordinator, Mukdahan Health Office, Thailand
 David Aylward, Executive Director, mHealth Alliance

3. Visions of the future Ta-Chien Chan National Ta

Ta-Chien Chan, National Taiwan University John S. Brownstein, HealthMAP co-creator, Assistant Professor, Children's Hospital Boston, Harvard Medical School, Harvard-MIT Division of Health Sciences and Technology

Thursday 28 January 2010

14.00 – 16.30 (Coffee Break included)

Parallel Session 1.3

Informing the response to chronic diseases

Moderator: Rafael Lozano, Professor, Global Health, Institute for Health Metrics and Evaluation

- Informing the response to chronic diseases: Thai National Health Examination Survey Wichai Aekplakorn, Associate Professor, Ramathibodi Hospital, Mahidol University
- Opportunities to understand bio-socio-environmental risks to illness across the life course: promises and perils of bio-banks
 Rajesh Kumar, Professor, PGIMER School of Public Health, India
- 3. Managing chronic disease: linking better data with better patient care. The role of electronic systems, such as electronic medical records (EMR), in managing large amounts of data more efficiently and the potential benefits in terms of more timely and accurate data for policy-makers and better patient information for health care workers, better clinical management. (Managing HIV/AIDS: Rwanda) Christopher Bailey, Coordinator, WHO

Thursday 28 January 2010

14.00 – 16.30 (Coffee Break included)

Parallel Session 1.4

Generating global evidence: births, deaths and causes of death

Moderator: Armin Fidler, Lead Advisor Health Policy and Strategy, The World Bank

- Improving vital statistics: possibility or pipe dream?
 Alan Lopez, Head, School of Population Health, University of Queensland, Australia
- Improving coverage and completeness of vital statistics

 A Kenyan experience
 Joyce W. Mugo, Director, Civil Registration Department, Kenya
- Tackling quality issues in vital statistics
 Sam Notzon, Special Assistant for Global Statistics, National Center for Health Statistics, USA
- Where civil registration systems are weak: demographic surveillance and verbal autopsy
 Peter Kim Streatfield, Head, Matlab Health and Demographic Surveillance
 ICDDR,B, Bangladesh
- The Sample Registration System in India Prasanta Mahapatra, Hon. President, Institute of Health Systems, India

Thursday 28 January 2010

14.00 – 16.30 (Coffee Break included)

Parallel Session 1.5

Choosing and using standards for interoperable information systems

Moderator: Moderator: William Hammond, Director, DCHI/DTMI

Speakers:

- 1. Interoperable information systems William Hammond, Director, DCHI/DTMI
- Use of standards in country systems
 Beatriz de Faria Leao, Chair Steering Committee, HL7 Brazil

 Andrew Grant, Director, Collaborative Research for Effective Diagnostics, Sherbrooke University, Canada
- Applicable standards and convergence Jennifer Zelmer, CEO, International Health Terminology Standards Development Organization (IHTSDO) Patrick Whitaker, Technical Officer, WHO

18.00 - 20.30

Welcome Dinner hosted by Royal Thai Government Welcome speech by Thai Health Minister and Mahidol University President

Special presentation by **Hans Rosling**, Director, Gapminder Foundation

Friday 29 January 2010 09.00 – 10.00

Plenary Session 2

- Review and main messages from the parallel sessions 1.1-1.5 (5 minutes)
- Stepping up to the plate: who does what to improve health information for monitoring health-related goals?

Moderator: Timothy Evans, Assistant Director-General, Information, Evidence and Research, WHO

Panelists:

- 1. **Frank Nyonator**, Director, Policy, Planning Monitoring and Evaluation Division, Ghana Health Service
- 2. **Ties Boerma**, Director, Department of Health Statistics and Informatics, WHO
- 3. **Daniel Low-Beer**, Unit Director, Performance, Impact and Effectiveness, The Global Fund to Fight AIDS, TB and Malaria
- 4. Sania Nishtar, President & CEO, Heartfile Organization
- 5. **Mark Landry**, Senior Informatics Specialist, PEPFAR, Office of the Global AIDS Coordinator

10.00 – 10.30 Coffee Break

Friday 29 January 2010 10.30 – 12.30

Parallel Session 2.1 Tracking country health systems performance

Moderator: Daniel Low-Beer, Unit Director, Performance, Impact and Effectiveness, The Global Fund to Fight AIDS, TB and Malaria

- Pakistan: Heartfile's framework for health systems performance assessment Sania Nishtar, President & CEO, Heartfile Organization
- South Africa: monitoring health system performance at subnational level Candy Day, Technical Specialist, Health Systems Trust
- Zambia: strengthening the analysis for annual health sector reviews through district assessments
 Christopher Simoonga, Deputy Director for Monitoring and Evaluation, Ministry of Health, Zambia
- Thailand: institutionalization of monitoring of health and health systems performance
 Phusit Prakongsai, Senior Researcher/Medical Doctor, International Health Policy Program (IHPP), Ministry of Public Health, Thailand
- Georgia: Health systems research to improve performance
 Tea Collins, Senior Health Systems Specialist, Global Forum for Health Research

Friday 29 January 2010 10.30 – 12.30

Parallel Session 2.2

Financial and human resources for HIS

Moderator: Keizo Takemi, Research Fellow; Professor, Japan Center for International Exchange; Tokai University

- Human Resources for Health Information Systems in Developing Countries
 William Hersh, Chair, Department of Medical Informatics and Clinical Epidemiology, Oregon Health & Science University
- eHealth Capacity Development in Africa
 Maurice Mars, Professor and Head of Department of Telehealth, University of Kwazulu Natal, South Africa
- eHealth Capacity Building for Rural Health Workers Lessons from the Trenches
 Alvin Marcelo, Director, National Telehealth Center, University of Philippines Manila
- HIS as a pre-requisite for health system strengthening efforts
 Brad Herbert, Managing Director, Herbert and Associates
- Strengthening Sierra Leone's National HIS Collaborative Approach
 Magnus Gborie, Director, Ministry of Health and Sanitation, Sierra Leone
- 6. National Health Accounts and HIS Charu Garg, Senior Health Economist, The World Bank

Friday 29 January 2010 10.30 – 12.30

Parallel Session 2.3

Universal access to health and health services: Essential information to track progress and support management. From measuring inputs to measuring impact?

Moderator: Adam Wagstaff, Research Manager, The World Bank

- Universal Access and Equity: Framing the Monitoring and Policy Feedback
 Adam Wagstaff, Research Manager, The World Bank
- Catastrophic impact of out-of-pocket payments for health care in Asia - evidence through the 1990s and 2000s
 J. Rachel Lu, Professor and Associate Dean, Chang Gung University, Taiwan
- Experiences of using health insurance claims database to support purchasing decisions – Estonian case Hannes Danilov, Chairman of Management Board, Estonian Health Insurance Fund
- Monitoring effectiveness of universal coverage in Thailand
 Supon Limwattananon, Associate Professor, Khon Kaen University
- 5. The Mexican Electronic Clinical Record Project Giota Panopoulou, Advisor to the Financing Director, Institute of Social Security, Mexico

Friday 29 January 2010 10.30 – 12.30

Parallel Session 2.4

Public stewardship of private providers: the role of health information systems

Co-Chairs: Frank Rijsberman, Director Program, Google David de Ferranti, President, Results for Development Institute

Panelists:

- 1. **Fola Laoye**, Chief Executive Officer, Hygeia-Nigeria Limited
- 2. **Richard Coker**, Professor of Public Health, London School of Hygiene & Tropical Medicine
- 3. **Phal Des**, Director, IT Center, Royal University of Phnom Penh
- 4. Krishnamurthy (Gopi) Gopalakrishnan, President, World Health Partners

12.30 – 13.30 Lunch

13.30 – 14.30

Plenary Session 3

- Review and main messages from parallel sessions 2.1 -2.5
- Enhancing global health security: information systems as the foundation of effective pandemic preparedness and response

Moderator: Miriam Were, Board of Trustees, UZIMA Foundation

Panelists:

- 1. **Guenel Rodier**, Director of International Health Regulations, WHO
- 2. **Bounlay Phommasack**, Deputy Director, Ministry of Health, Lao PDR
- 3. **Richard Cash**, Senior Lecturer on International Health, Harvard School of Public Health and former Prince Mahidol Awardee

Friday 29 January 2010

15.00 – 17.00

Parallel Session 3.1

Improving transparency through collaboration across sectors

Moderator7: Richard Manning, Chairman of the HMN Board

Panelists:

- 1. **Mohamed-El-Heyba Berrou**, Manager of the PARIS21 Secretariat, OECD
- 2. Jasap Dam Nagari-Popoitai, Advisor, PSRMU, Department of Prime Minister & National Executive Council, Papua New Guinea
- 3. Alan Lopez, Head, School of Population Health, University of Queensland, Australia
- 4. **Ivo Njosa**, Coordinator Health Information Systems; Health, Nutrition and Population Human Development Network, The World Bank

Parallel Session 3.2

Exploring the frontiers of health information in a petabyte age

Moderator: Renata Bushko, Director, Future of Health Technology Institute

- Petabyte-age in Health 2020
 Gabe Rijpmpa, Industry Health Director, APAC Public Sector, Microsoft Corporation
- 2020 Scenarios of Frontiers of Health Information Technology: Personal Status Monitoring James DelloStritto, Principal Researcher, R&D, Blue Highway LLC
- A vision for enhancing public health and addressing health inequalities through Information and Communications Technologies (ICT's)
 M. Chris Gibbons, Associate Director, Johns Hopkins Urban Health Institute
- Strategies for Positive Outcomes: Can Information Technology Make a Difference in Health in Africa Julia Royall, Chief, Office of International Programs, U.S. National Library of Medicine/ National Institutes of Health
- Social Implications of Petabyte Age through Evolution of mHealth Mridul Chowdhury, CEO, Click Diagnostics Inc.

Friday 29 January 2010 15.00 – 17.00

Parallel Session 3.3

Measuring the un-measurable: death, disease, health and happiness

Moderator: Laragh Gollogly, Managing Editor, Bulletin of the World Health Organization

- Measuring Health: Disease Perspective Timothy Evans, Assistant Director-General, Information, Evidence and Research, WHO
- 2. Measurement of Health: Well-being Perspective Ronald Colman, Executive Director, Genuine Progress Index for Atlantic Canada (GPI Atlantic)
- Measuring the Immeasurable: Bhutan's Experiment with Measuring Gross National Happiness
 Dorji Penjore, Deputy Director, Centre for Bhutan Studies, Bhutan
- Country Perspective: Thailand
 Apirak Kosayodhin, Advisor to Prime Minister of Thailand

Friday 29 January 2010 15.00 – 17.00

Parallel Session 3.4

Harmonizing multiple health information systems through effective system analysis and design

Moderator: David Ross, Executive Director, Public Health Informatics Institute

- 1. Introduction David Ross, Executive Director, Public Health Informatics Institute
- Presentations of developing country eHealth and public health information systems infrastructure focusing on the need
 Richard Gakuba, National e-Health Coordinator, Ministry of Health, Rwanda
- Examples of developed country implementations focusing on design and architectural elements Michael Bainbridge, Principal Consultant, ASE Ltd Ron Parker, Group Director, EHRS Architecture, Canada Health InfoWay Ngai-Tseung Cheung, Chief Medical Informatics Officer, Hospital Authority, Hong Kong
- Methods for improving design Systematic and rational design: David Lubinski, Program Director, PATH Current initiatives in developing countries -Feedback from Technical Briefing: Christopher Seebregts, Senior Manager, Medical Research Council, South Africa

Friday 29 January 2010 15.00 – 17.00

Parallel Session 3.5

Managing complex data in health crises: challenges for national health information systems

Moderator: Michael St. Louis, Associate Director for Science, Centers for Disease Control and Prevention, USA

Speakers:

- Health Information in Heart of the Storm: Novel H1N1 in Mexico, 2009
 Juan Eugenio Hernandez Avila, Director, Information Center for Decisions in Public Health, National Institute of Public Health
- Situation Awareness what can Health Learn from Other Sectors
 Mica Endsley, President, SA Technologies
- Early Warning and Response System, EWARS, a critical component of health information system in complex emergencies situation Augusto Pinto, Medical Epidemiologist, WHO, Thailand
- 4. Spatially Enabled Decision Support Systems: Enabling Better Humanitarian Coordination Keith Doyle, Senior Information Officer, iMMAP
- Strategic Information Flow for Health Emergencies and Response, Ethiopia Tsehaynesh Messele, Director General of EHNRI, Federal Ministry of Health, Ethiopia

17.00 – 19.00 Call to Action Finalization Session

Saturday 30 January 2010

9.00 - 10.30

Conference Synthesis Session

Summary, Conclusion and Policy Recommendations

- Leading Rapporteur Team
- Toomas Palu, Senior Health Specialist, The World Bank
- Viroj Tangchareonsathien, Director, International Health Policy Programme, Ministry of Public Health, Thailand

10.30 – 11.00 Coffee Break

11.00 – 12.00 Call to Action Closing Session

12.00 – 13.00 Lunch

13.30 – 16.30 International Organizing Committee Meeting

Prince Mahidol Award Conference 2010

KEYNOTE SESSION




ANNE MILLS

PRINCE MAHIDOL AWARD LAUREATE 2009 HEAD OF DEPARTMENT OF PUBLIC HEALTH AND POLICY LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE UNIVERSITY OF LONDON

Anne Mills is Professor of Health Economics and Policy at the London School of Hygiene and Tropical Medicine and Head of the Department of Public Health and Policy. She has over 35 years' experience of the health systems of low and middle income countries, and has researched and published widely in the fields of health economics and health systems. Her most recent research interests have been in the organisation and financing of health systems including evaluation of contractual relationships between public and private sectors, and in economic analysis of disease control activities and the appropriate roles of public and private sectors, especially for scaling up malaria control efforts. She has had extensive involvement in supporting capacity development in health economics in low and middle income countries, for example through supporting the health economics research funding activities of the WHO Tropical Disease Research Programme, and Chairing the Board of the Alliance for Health Policy and Systems Research. She founded, and is Director of, the Health Economics and Financing Programme, which together with its many research partners, has an extensive programme of research focused on increasing knowledge of how best to improve health systems in low and middle income countries. She has advised multilateral, bilateral and government agencies on numerous occasions; acted as specialist advisor to the House of Commons Select Committee on Science and Technology's enguiry into the use of science in UK international development policy; was a member of WHO's Commission on Macro-economics and Health and co-chair of its working group 'Improving the health outcomes of the poor'; and co-chaired one of the two Working Groups for the 2009 High Level Taskforce on Innovative Finance for Health Systems co-chaired by Gordon Brown and Robert Zoellick. In 2006 she was awarded a CBE for services to medicine and elected Foreign Associate of the US Institute of Medicine. In 2009 she was elected Fellow of the UK Academy of Medical Sciences and won the Prince Mahidol Award in the field of medicine.



KEIZO TAKEMI

RESEARCH FELLOW; PROFESSOR JAPAN CENTER FOR INTERNATIONAL EXCHANGE TOKAI UNIVERSITY

Prof. Keizo Takemi is Senior Fellow of Global Health and Human Security at the Japan Center for International Exchange. He was a research fellow at the Harvard School of Public Health in 2007-09, and became Special Advisor to the Sasakawa Memorial Health Foundation in August 2009. Prof. Takemi was a member of the House of Councillors (Liberal Democratic Party) in the Japanese Diet for 12 years until August 2007 and served in the Abe Cabinet as Senior Vice Minister for Health, Labour and Welfare. He led the initiative to establish a UN Trust Fund for Human Security as State Secretary for Foreign Affairs in 1999 and served as a member of the High Level Panel on UN System-Wide Coherence in Areas of Development, Humanitarian Assistance and Environment. He received his graduate degree from Keio University and, since 1995, he has concurrently been a professor at the Tokai University's Research Institute of Science and Technology.

PLENARY SESSION 1:

HEALTH INFORMATION SYSTEMS:

THE CASE, THEIR VALUE, THE CURRENT AND THE FUTURE CHALLENGES



SESSION WILL COVER THE FOLLOWING ISSUES:

1) Making the case --- "better information leads to better health"

• Clarity on why good health information systems matter

2) The current state of health information systems globally

- Coming to terms with the Health Information System 'elephant
- The missing parts --- the information paradox, shortfalls in coverage
- Not using what's there -- drowning by numbers, poor use of information
- Disorganized and duplicative demands
- Over-resourced and under-resourced

3) Looking ahead: Promises and perils of information systems in the 21st Century

- Everyone counts: ensuring all births and deaths are registered
- Health Information for all: The empowered and protected consumer, the informed decision maker, providers held to account
- A new era in information systems design facilitated by the ICT revolution: bridging the clinical-population health divide...a single, continuous health record across the life course



RICHARD HORTON

EDITOR-IN-CHIEF THE LANCET

Richard Horton is Editor-in-Chief of The Lancet. He was born in London and is half Norwegian. He qualified in physiology and medicine from the University of Birmingham in 1986. After general medical training and research in Birmingham and London, he joined The Lancet in 1990, moving to New York as North American Editor in 1993. He was the first President of the World Association of Medical Editors and is a Past-President of the US Council of Science Editors. He is an honorary professor at the London School of Hygiene and Tropical Medicine, University College London, and the University of Edinburgh. He has received Honorary Doctorates in Medicine from the University of Birmingham, UK, and the University of Umea, Sweden. He is a Fellow of the Royal College of Physicians and a Founder Fellow of the UK's Academy of Medical Sciences. In 2004, The Lancet won the UK's Medical Publication of the Year. In 2005 he wrote the report for the Royal College of Physicians' inquiry into the future of medical professionalism -Doctors in Society. He also chaired and wrote the Royal College of Physicians' 2009 report into physicians and the pharmaceutical industry - Innovating for Health. He co-chairs the College's Medicine's Forum; is a Council Member of the Academy of Medical Sciences; and is a Board Member of the Health Metrics Network. In 2007, he received the Edinburgh Medal for professional achievements judged to have made a significant contribution to the understanding of human health and wellbeing. In 2008, he was appointed a Senior Associate of The Nuffield Trust, a think tank for research and policy studies in health services. In 2009, he was awarded the Dean's Medal by Johns Hopkins School of Public Health for activism and leadership in addressing the needs of poor women and children worldwide. He has a strong interest in issues of global health. He has been a medical columnist for The Observer and writes regularly for the Times Literary Supplement and New York Review of Books. A book about controversies in modern medicine, Health Wars, was published in 2003. He enjoys cooking and arguing, and lives in London with his wife, Ingrid, a paediatrician, and their nine-year old daughter, Isobel.

AR MA RO

ARIEL PABLOS-MENDEZ

MANAGING DIRECTOR ROCKEFELLER FOUNDATION

"Dr. Ariel Pablos-Mendez, a Professor of Clinical Medicine and Clinical Epidemiology at Columbia University in New York, has worked in global health with the World Health Organization and The Rockefeller Foundation, where he is currently Managing Director and driving the Foundation's new initiative on e-Health and Transforming Health Systems."

Dr. Ariel Pablos-Méndez is Managing Director at The Rockefeller Foundation, and Professor of Clinical Medicine and Epidemiology at Columbia University in New York. Previously, he served as Director of Knowledge Management at WHO in Geneva, working to bridge the know-do gap in public health and promoting e-Health. He returned to the Rockefeller Foundation in 2007, where he was a program officer from 1998 to 2004 spearheading public-private partnerships in R&D for diseases of poverty and the Foundation's strategy on AIDS and human resources for health. He now drives the Foundation's initiative on the transformation of health systems for universal coverage. Dr. Pablos-Méndez received his M.D. from the University of Guadalajara's School of Medicine (Mexico) and his M.P.H from Columbia University's School of Public Health (New York).

JULIAN SCHWEITZER



ACTING VICE PRESIDENT THE WORLD BANK

Julian Schweitzer is Acting Vice President, Human Development Network and Director, Health Nutrition and Population of the World Bank.

Immediately prior to his current appointment, Julian was the Director of the Human Development Sector in the South Asia Region of the World Bank, responsible for the Bank's operations in health, nutrition, population, education and social protection. During his career in the Bank, he has also worked in the Middle East and North Africa, Latin America and the transition economies of Europe, managing operations in health, education, and social protection. He has also worked as the Operations Director in the Bank's East Asia and Pacific region and as the Bank's Country Director based in Russia.

While working in the South Asia Region, he focused on developing sector wide approaches to mobilize external financing effectively in support of a single country health strategy. He restructured and strengthened the Bank's regional HIV/AIDS engagement with clients and external partners, while also strengthening the Bank's advisory and financial role.

He has extensive operational and management experience of health and development issues in different parts of the world. His health sector interests include health finance and health systems strengthening.

Before joining the Bank, Mr. Schweitzer worked in the public and private sectors in the UK and India.

He holds a Ph.D. from the University of London and has authored numerous articles and essays on economic and human development.

SALLY STANSFIELD



EXECUTIVE SECRETARY HEALTH METRICS NETWORK

Sally Stansfield is the Executive Director of the Health Metrics Network (HMN), a global partnership founded to improve the supply and use of information to improve decision making for health in developing countries. For HMN's global network and for its host, the World Health Organization, Dr. Stansfield manages the technical and financial contributions of HMN partners to accelerate reform of health information systems for improved health outcomes.

Prior to 2006, Dr. Stansfield was the Associate Director for Global Health Strategies of the Bill & Melinda Gates Foundation. She draws upon more than 30 years of clinical and public health practice, experience in research agencies, universities, governments, non-governmental organizations, and multilateral agencies. Dr. Stansfield's areas of expertise include public health research, policy, strategic planning, program design and development, evaluation, and the development of health information systems. She has designed and managed programs for the US Centers for Disease Control, the US Agency for International Development and Canada's International Development Research Centre and has advised governments in Bangladesh, Cambodia, DR Congo, Ethiopia, Malawi, many other countries, primarily in Asia and Africa.

Her many awards include the Alpha Omega Alpha medical honorary, the International College of Surgeons Award for Scholarship, the Public Health Service Distinguished Service Commendation, a Fulbright Fellowship, and the Yale Tercentennial Medal.

JEANETTE VEGA



VICEMINISTER MINISTRY OF HEALTH, CHILE

Dr. Jeanette Vega is the Vice minister of Public Health in Chile since January 2008. Before going back to her country in December 2007, she was the Director of the Department of Equity, Poverty and Social Determinants of Health of the World Health Organization where she led the WHO Secretariat of the Commission of Social Determinants of Health. A Chilean born, she received her medical degree and her family medicine training from the University of Chile. Subsequently she completed a Doctor in Public Health training at the University of Illinois at Chicago. In 2000 she joined the Executive committee for Health Reform that was set up by the President in office at the time to restructure the Chilean Health system. After completing the work she was appointed as Director of the National Institute of Public Health. She joined WHO in September 2003 and was designated as Department Director in January 2006. Her overall vision is of Public health contributing to everyone reaching their full potential for health independent of their social and economic position and of health systems focusing on achieving equitable access to care to all people in society.

PARALELL SESSION 1.1:

RENEWING POLICY AND LEGISLATION FOR HEALTH INFORMATION



LAW, ETHICS & GOVERNANCE IN E-HEALTH: CAN EXPERIENCE IN HIGH INCOME COUNTRIES ASSIST LOW INCOME COUNTRIES?

ROGER S. MAGNUSSON PROFESSOR, FACULTY OF LAW, UNIVERSITY OF SYDNEY, AUSTRALIA

What are some of the legal, ethical and governance issues that developing countries need to consider as they invest in e-health? Can the experience of high income countries, and the lessons they have learned over the past decade provide any assistance to lower-income countries as they invest in e-health as a tool for development?

This is not a straight-forward question. For example, to what extent are the e-health goals of developed countries appropriate or well suited to developing countries? Should low income necessarily countries aspire to what high income countries aspire to when it comes to investing in e-health? Is it patronizing to suggest that their priorities ought to be different? These questions are highly relevant when it comes to identifying the legal, ethical and governance issues that are most relevant for low income countries to consider.

Figure 1 shows some of the core applications of e-health identified by the World Health Organisation's Global Observatory for e-Health.

Telehealth:	 improving clinical treatment using telecommunications links electronic transmission of x-rays, diagnostic images 	
Electronic health records:	longitudinal health care records linking data from multiple sources and sites of care	
Clinical and decisional supports:	 clinical reminders computer-assisted prescription systems (drug interaction, drug-dose alerts) clinical databases personal digital assistants (PDAs) for clinical practice in the field 	
e-Health & capacity building:	distance learning using health ITC	
e-Health & public health functions:	 dissemination of health alerts use of health ITC in health promotion use of PDAs to capture population health data in the field 	
e-publishing:	 open source publishing of: health information for the general public, and target groups medical and health literature to health professionals 	
Improving efficiency of administrative and management functions:	 electronic prescribing; e-referrals electronic test ordering on-line management of supply chain transactions (drugs, equipment) 	

FIGURE 1: SOME CORE APPLICATIONS OF E-HEALTH

These e-health applications range across a spectrum. Some – like longitudinal, federated, fully integrated electronic health records systems linking multiple sites of care – are highly ambitious and remain a stretch goal in most developed countries.¹ Others, like open source publishing, distance learning using ICT, and certain forms of telehealth ought to be achievable through planning and investment in any country with a functioning telecommunications infrastructure.

FACTORS DRIVING INVESTMENT IN E-HEALTH IN HIGH AND LOW INCOME COUNTRIES: SIMILARITIES AND DIFFERENCES

There are some commonalities in the factors driving interest and investment in health ICT in high and low income countries. E-health reform has the capacity to improve patient health outcomes by improving the timely availability of a patient's health information for treatment decisions, by providing decisional support products to improve evidence-based decision-making, and by improving access to health services (eg through telemedicine). E-health also has the capacity to reduce duplication and costs. Nevertheless, some important differences between the e-health environment in high and low income countries should not be overlooked.

¹ In the United States, a survey of physicians found that in late 2007/early 2008, only 4% had a fully-functional electronic health records system in operation; a further 13% had a basic system. 83% of respondents had no system: Catherine M. DesRoches, Eric G. Campbell, Sowmya R. Rao, Karen Donelan, Timothy G. Ferris, Ashish Jha et. al., "Electronic Health Records in Ambulatory Care - A National Survey of Physicians", New England Journal of Medicine 2008; 359: 50-60. In a national survey of hospitals conducted in 2008, 12% of hospitals had implemented electronic clinicians' notes across all hospital units, 17% of hospitals had introduced a computerized system for the ordering of medications. Overall, only 2.9% of hospitals had a "comprehensive electronic-records system implemented across all major clinical units". A further 7.9% had introduced a basic electronic records system that included electronic physicians' notes and nursing assessments in at least one department: Ashish K. Jha, Catherine M. DesRoches, Eric G. Campbell, Karen Donelan, Sowmya R. Rao, Timothy G. Ferris et. al., Use of Electronic Health Records in U.S. Hospitals", New England Journal of Medicine 2009; 360: 1628-1638, at 1631.

In developed countries like my own, the centre of gravity of discussions about e-health reform has been the prospect of improving delivery of health care services through an integrated electronic health records capability. For example, drug interaction alerts built into EHR systems have the capacity to reduce adverse outcomes in patients who suffer from chronic disease and are highly medicated.² The high burden of chronic disease in developed countries has also led to a lack of coordination and to fragmented communication between different health care providers. EHRs can help to coordinate care for chronic conditions and improve the information available at all sites of care.

Although care of chronic conditions is a major factor driving interest in e-health in high income countries, low income countries face additional challenges. For example, electronic health records may be of limited assistance to a young rural mother who cannot afford the time and expense of taking her dehydrated and listless baby to the nearest doctor. This example also illustrates another important difference between high and low income countries. In high income countries, *payers* – whether they are private insurers, governments or employers – all want to reduce costs, and to stabilise the unstoppable demand for health care services that accounts for an ever-increasing percentage of GDP. Increasingly, payers only want to pay for what can be shown to actually lead to improved health outcomes for patients.

In low income countries, governments and their development partners (including development agencies and foreign donor governments) also want to see efficient use of limited resources with clear benefits for patients. Yet low income countries also need to *create demand* in under-served populations who lack access to health care services. The nature of the investment in e-health required in order to meet the needs of poor, *under-served* populations may be quite different to that required for higher income populations where health care is available but not sufficiently coordinated.

² In Australia, for example, between 2001/02 and 2005/06, the number of hospital separations attributed to "adverse effects of drugs, medicaments and biological substances" rose from 1.1 to 1.3 per 100 separations: Australian Institute of Health and Welfare (AIHW), *Australia's Health 2008*, Canberra: AIHW, 2008, pp 355-357.

Ultimately, health ICT "is a tool, not a goal".³ E-health will not magically fix a health system that is broken or non-functioning. An electronic system for ordering medicines and pharmaceuticals will not improve patient care if transport links are inefficient or if government red tape delays the process or if shipments vanish along the supply chain due to corruption or if the medicines are unaffordable. Installing new software for health records in a hospital will achieve little if the server is usually down because there are no technicians to fix it or because the electrical supply is intermittent.

At the same time, health ICT does allow for needs to be met in new ways. This is especially important when it comes to ACCESS:

- access to health care services,
- access to quality health information through a computer for health professionals and members of the public, and
- access to educational opportunities through distance learning.

In identifying priority areas for investment in e-health services in low income countries, it is helpful to ask the following questions. What are the unmet needs of the population that e-health could help to meet? What are the functions that could be effectively discharged through e-health, and which will have the most significant impact in terms of health improvements at the population level? The functions that e-health services might help to discharge do not revolve only around health care services. They also extend to *public health functions*, including those shown in Figure 2:

³ Carol C. Diamond, Clay Shirky, "Health Information Technology: A Few Years of Magical Thinking?" *Health Affairs* 2008; *27, no. 5:* w383-w390, at w383. The authors state:

[&]quot;[e-Health] is a tool, not a goal. Success should not be measured by the number of hospitals with computerized order entry systems or patients with electronic personal health records. Success is when clinical outcomes improve. Success is when everyone can learn which methods and treatments work, and which don't, in days instead of decades."

Evidence	Surveillance, monitoring and investigation of population health risks
Health protection & assurance	Mitigating risks to population health; discharge of legislative responsibilities; performance of regulatory functions
Health promotion	Education; partnerships and policies to support and empower individual and community health efforts
Financing	Contracting for, or directly providing public health services
Training	Training and education; capacity building for population health
Research	Supporting and funding national research capacity for population health

FIGURE 2: HEALTH ICT AND CORE PUBLIC HEALTH FUNCTIONS

A SIMPLIFIED MODEL FOR IDENTIFYING LEGAL AND GOVERNANCE CHALLENGES FOR E-HEALTH

Figure 3 provides a simple model for thinking about the subtly varying challenges that e-health creates in both low and high income countries. It consists of three overlapping tiers.

FIGURE 3: SIMPLIFIED MODEL FOR IDENTIFYING LEGAL AND GOVERNANCE CHALLENGES FOR E-HEALTH

TIER 1 Laws and policies for an effective ITC environment capable of carrying broadband and telecommunications services	 Eg: licensing of the spectrum licensing of telecommunications carriers and carriage service providers financing and infrastructure (ITC capabilities) 	7	Internat
TIER 2 Laws and policies for the effective delivery of e-health services	 interoperability: standards development and implementation financing of, infrastructure for e-health capabilities legal infrastructure; eg: regulation of cross-border practice & prescribing; indemnity/ malpractice insurance 	lational context	ional or global co
TIER 3 Laws and policies to ensure that e-health services are fully realized and comply with ethical goals and principles	 data security privacy & confidentiality equitable access policies for multilingualism liability for quality of care 		ntext

The first tier of governance relates to the regulation of telecommunications and the creation of a contestable environment (or at least a functioning environment) for the provision of telecommunications services, including broadband links and mobile telephony. Tier 1 governance also includes the licensing of the spectrum, and the licensing of telecommunication carriage service providers.

As regulators, governments have the capacity to enshrine the values of equity, access, and coverage into a competitive telecommunications system.⁴ Ultimately, the goal of Tier 1 governance needs to be nationwide coverage, universal access, affordability, and service quality. These are the most fertile conditions for reaping the benefits of what health ICT makes possible for the health sector.

A functioning telecommunications environment provides the foundation for health-related applications. Tier 2 governance moves to the particular challenges that require resolution in order to deliver e-health services across telecommunications networks. In addition to the technical challenges of achieving interoperability, Tier 2 governance extends to the legal infrastructure required to support e-health functions, such as cross-border practice and prescribing.

Tier 3 governance relates to the citizen protection and equity issues that need to be addressed to encourage trust and demand for e-health services and to ensure that e-health initiatives meet ethical principles and goals. Examples include laws and policies for data security, privacy and confidentiality, multilingualism, and equity in access to services.

⁴ In Australia, for example, the *Telecommunications (Consumer Protection and Service Standards*) Act 1999 (Cth) establishes a "universal service regime" which aims to ensure that all people in Australia, wherever they live, have reasonable access on an equitable basis to "standard telephone services", pay-phones, and "prescribed carriage services" (s 9). Under this Act, the Minister may designate "primary universal service providers" who must satisfy these service obligations within "universal service areas" (s 12A). The legislation includes a "customer service guarantee" which consists of performance standards which carriage service providers must meet. Compensation is payable to consumers when standards are not met (s 113).

To complete this model, we need to draw attention to the fact that the use of e-health as a tool for health development raises issues of international governance that tend not to arise for high income countries, where e-health reform is largely a national (rather than transnational) effort.

The remainder of this paper provides examples of the experience of high income countries (particularly Australia, and the United States) in addressing issues at Tiers 2 and 3 of the governance model, and draws out some implications for low income countries.

TIER 2 REGULATION: E-HEALTH REFORM: THE CHALLENGE OF ACHIEVING INTEROPERABILITY

Realising e-health is an exercise in managing complexity. Progress in developed countries has been far slower than we were led to believe a decade ago.⁵ Achieving interoperability is a pre-condition to realizing the vision of e-health in developed countries. Interoperability can be seen in terms of the twin challenges of *standards development, and standards implementation,* and the gap between them. Figure 4 (below) summarises the key elements involved in achieving interoperability.

⁵ For example, Michael Cross, "Can the NHS Get Connected?" *British Medical Journal* 2009; **339**: 778-779. In Australia, in 2005, the National e-Health Transition Authority was established by Commonwealth, State and Territory governments as a not-for-profit company to advance Australia's e-health agenda, following the failure of the previous Commonwealth-led e-health strategy, known as HealthConnect: see David More, "Health Connect is Dead – So Now What?" 1 February 2006, at: <u>http://cpd.org.au/</u> <u>article/health-connect-dead-so-now-what%3F</u>

FIGURE 4: WHATARETHEELEMENTSOF "INTEROPERABILITY" IN E-HEALTH SYSTEMS? A SIMPLIFIED MODEL*

	DEVELOPMENT AND ENDORSEMENT OF STANDARDS AND SPECIFICATIONS		
Standards development $\rightarrow \rightarrow \rightarrow$ Standards endorsement $\rightarrow \rightarrow \rightarrow$ Im	Clinical communication	 Clinical terminologies: standardising clinical concepts and terms used to describe diagnoses, therapies, procedures, identification and dosage of medications etc: to ensure consistent and accurate interpretation by clinicians and e-health systems Specifications for transmission, storage of diagnostic imaging Clinical information: standardization of the content and format of patient data in patient referrals, discharge summaries, pathology results, prescriptions etc. 	
	Identification	• Unique identifiers for patients, health care providers and organisations: to ensure positive identification, ensure privacy, accurately link health information to a specific patient, was received by the right person etc.	
	Technical standards	 Standards for how priority health information is captured by IT systems to facilitate transmission of discharge summaries, referrals, prescriptions etc. Secure messaging: standards and specifications for secure, authorised transmission of patient health data between authenticated health professionals (users). Ensures compatibility between e-health systems 	
	Endorsement and recommendation by national authority	 Processes for formal designation of standard and specifications; Consultation with IT industry and health industry users (software developers, suppliers, purchasers and users – including clinicians) to ensure that standards and specifications meet the needs of developers, suppliers, purchasers and users Publication of recommended/endorsed standards 	
plem	IMPLEMENTATION OF STANDARDS**		
nentation & conformance	Adoption	 The decision to implement e-health standards within the health care organization The decision to implement e-health standards and specifications in e-health software products and services (by software developers, suppliers) 	
	Uptake and implementation	Planning for, and implementation of, standards: within products, services and healthcare transactions	
	Conformance and compliance	 Schemes for assessing and certifying conformance: ie the implementation of e-health standards and specifications within e-health software and services Compliance by health care organizations and e-health service providers with laws, codes of conduct, industry standards (and any other mandates relating to e-health standards) 	

* This figure draws extensively on work and concepts of Australia's National E-Health Transition Authority

⁽NEHTA); see: <u>http://www.nehta.gov.au</u> ** For further information, see NEHTA, *Supporting National E-Health Standards Implementation: Adoption, Uptake & Implementation* (Version 1.0 – 31 January 2007), and the *NEHTA Strategic Plan* (2009/10 to 2011/12).

Standards development is a consultative, but technical process of identifying and formalising the standards and specifications that will deliver the capability of interoperable health care records. Standards implementation, on the other hand, is the process that results in the uptake of standards in products, services, and organizations. The challenge is to infuse standards implementation into the development of new products and in the procurement and tendering decisions of health care organizations. This is not an academic exercise. It involves changing culture and the behaviour of a wide range of actors, within rapidly evolving markets for e-health products and services: this is a very significant challenge facing developed countries.⁶

Developed countries have implemented a range of governance mechanisms to encourage progress towards interoperability. These include intergovernmental agreements, creating and tasking agencies, passing legislation and creating economic incentives.

EXAMPLE 1: INTERGOVERNMENTAL AGREEMENTS

In December 2009, federal, state and territory governments in Australia entered into a National Partnership Agreement on e-Health. This agreement defines the specific roles of governments in a federal system, including their respective financial contributions over time, and commits each of them to pass

⁶ See, for discussion, National e-Health Transition Authority (NEHTA), Supporting National E-Health Standards Implementation: Adoption, Uptake & Implementation, Verson 1.0 (31 January 2007): Sydney, NEHTA, 2007, available at: www.nehta.gov.au NEHTA states: "Successful standards adoption and ultimately standards implementation is essential for NEHTA to achieve its objectives. Despite encouraging the implementation of health informatics standards, minimal progress has occurred to date. The Australian Government Department of Health and Ageing has funded free electronic downloads of...standards through Standards Australia. The financial barrier to accessing Australian health informatics standards has been eliminated. However, progress in relation to implementation of these standards is still slow. The current rate of progress can be attributed to a lack of continuity in the standards chain especially between standards development and standards implementation. Bridging the gap between those who develop the standards and those who implement them requires the contribution of developers, suppliers, purchasers and implementers" (at 4).

aspects of a national legislation scheme establishing national healthcare identifiers service covering health providers, healthcare organizations, and patients.⁷ The national Healthcare Identifiers Service is a foundation service intended to accelerate progress towards a national electronic health records system.

EXAMPLE 2: FINANCIAL INCENTIVES

In Australia, the federal government introduced the Practice Incentives Program e-Health Incentive, a budget measure intended to encourage community-based medical practitioners to adopt the secure messaging requirements that will provide the backbone for electronic health records.

The Practice Incentive Program is part of a national strategy to move from payment models that financially reward community medical practices for their throughput (number of patients seen) towards a model that better encourages guality of care, with performance payments based on indicators that serve national priorities.⁸ To gualify for the PIP e-health incentive, each medical practice and medical practitioner must apply for a Public Key Infrastructure (PKI) certificate. The practice must also obtain a secure messaging capability from an eligible supplier, and individual practitioners must acquire access to a range of electronic clinical resources. These elements are intended to provide the basis for a range of e-health transactions as technology develops, including secure on-line exchange of discharge summaries, pathology reports and specialist reports, e-prescribing, electronic referrals and pathology orders.

⁷Council of Australian Governments (COAG), *National Partnership Agreement* on *E-Health*, 7 December 2009, at: <u>http://www.egov.vic.gov.au/focus-on-</u> <u>countries/australia/trends-and-issues-australia/e-health-australia/national-</u> <u>partnership-agreement-on-e-health-council-of-australian-governments-co-</u> <u>ag.html</u> For a copy of the draft federal legislation establishing the scheme, the *Healthcare Identifiers Bill 2010* (Cth), see: <u>http://www.health.gov.au/inter-</u> <u>net/main/publishing.nsf/Content/consultation-exposuredraftlegisation</u> See also Commonwealth of Australia, *Building the Foundation for an e-Health Future: Update on Legislative Proposals for Healthcare Identifiers*, issued by the Australian Health Ministers' Conference, November 2009, at: <u>http://www. health.gov.au/internet/main/publishing.nsf/Content/E7C1554B9FBFB924C</u> <u>A25768400812AAF/\$File/BuildingFoundations.pdf.</u>

⁸ See Medicare Australia, "Practice Incentives Program", at: <u>http://www.</u> medicareaustralia.gov.au/provider/incentives/pip

EXAMPLE 3: CREATION AND TASKING OF AGENCIES

In Australia, the National E-Health Transition Authority (NEHTA) is a not-for-profit company established by Australian governments to "lead the uptake of e-health systems of national significance".⁹ NEHTA's role includes acting as the conduit for communication between the developers and implementers of e-health standards, and publishing its recommendations in a national catalogue of e-health standards.¹⁰ Its role also includes delivering a number of specific foundation services for e-health in Australia, including a national Healthcare Identifier Service and a secure messaging service (the enablers for secure exchange of health information).¹¹

¹⁰ NEHTA states: "NEHTA acts as the aggregator of demand in relation to standards and specifications for e-health in Australia. NEHTA engages with suppliers, developers, purchasers and implementers to ensure that the standards NEHTA recommends and specifications developed meet the needs of the industry; providing assurance that a fit-for-purpose assessment for applicability to the e-health environment....NEHTA actively encourages suppliers, developers, purchasers and implementers to be involved in the standards development process. This simplifies uptake of standards as the supplier, developer, purchaser and implementer has contributed to the development of the standards that they would then uptake. This is an invaluable opportunity for the users of standards and the standards developers, to gain the benefit of the experiences of each other": NEHTA, *Supporting National E-Health Standards Implementation: Adoption, Uptake & Implementation,* Verson 1.0 (31 January 2007): Sydney, NEHTA, 2007, p 17, available at: www.nehta.gov.au.

¹¹ NEHTA, *NEHTA Strategic Plan 2009/10 to 2011/12,* October 2009, pp 9-16.

⁹ NEHTA's Purpose Statement is: "To lead the uptake of e-health systems of national significance; and To coordinate the progression and accelerate the adoption of e-health by delivering urgently needed integration infrastructure and standards for health information": NEHTA, *NEHTA Strategic Plan* 2009/10 to 2011/12, October 2009, at: <u>http://www.netha.gov.au</u>

One of the largest challenges identified by NEHTA has been to engage developers, suppliers, purchasers and various industry associations in order to improve conformance with the standards and specifications that will provide interoperability and thus the capacity to deliver e-health functions.¹²

EXAMPLE 4: THE ROLE OF LEGISLATION AND LEGAL MANDATES

Legislation can serve as a vehicle to introduce all of the governance strategies mentioned above. The best example here is President Obama's economic stimulus package, the *American Recovery and Reinvestment Act of 2009,* which includes two Titles on health information technology.¹³

Title XIII establishes the Office of the National Coordinator for Health Information Technology within the Department of Health and Human Services. The extensive functions of this Office are summarized in Appendix A. They include:

 reviewing and indorsing standards for exchange and use of health information that are recommended by the HIT Standards Committee;

¹² NEHTA, Supporting National E-Health Standards Implementation: Adoption, Uptake & Implementation, Verson 1.0 (31 January 2007): Sydney, NEHTA, 2007, p 21. For example, in Australia, industry associations representing medical software and compliance, conformance and accreditation recently reached agreement on a common approach to conformance and accreditation: see <u>http://www.nehta.gov.au/connecting-australia/cca</u>

¹³ See American Recovery and Reinvestment Act of 2009, Public Law 111-5 (February 17, 2009), Title XIII (Health Information Technology), 123 Stat. 115, 226-279; Title IV (Medicare and Medicaid Health Information Technology), 123 Stat. 115, 467-496, at: http://www.gpo.gov/fdsys/pkg/PLAW-111publ5/ content-detail.html For discussion of health and e-health initiatives in this legislation, see Robert Steinbrook, "Health Care and the American Recovery and Reinvestment Act" New England Journal of Medicine 2009; 360: 1057-1060. For the Congressional Research Service Summary of the Act (including both Titles), see: http://www.govtrack.us/congress/bill.xpd?bill= h111-1&tab=summary. For a review of the legislation prepared by the Centers for Medicare and Medicaid Services, see U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, Fact Sheet: "Medicare and Medicaid Health Information Technology: Title IV of the American Recovery and Reinvestment Act", 16 June 2009, at: http://www. cms.hhs.gov/Recovery/11 HealthIT.asp.

- maintaining a federal health IT strategic plan which aims to achieve an electronic health record for every person in the United States by 2014;
- preparing a report identifying lessons learned by major public and private health care systems as they implement health ICT;
- The National Coordinator must also identify practices to increase the adoption of health ICT in under-served communities, and assess the impact of health ICT in communities with health disparities.

The Act requires federal agencies to use health information technology systems that have been adopted by the Secretary of Health and Human Services. It also requires contractors including health plans and health care providers who contract with federal agencies for federally administered or sponsored health care programs to use health ICT systems that meet the standards and specifications adopted by the Secretary.

But by far the most significant financial incentive for e-health is the \$17 billion available as incentive payments to health professionals and hospitals treating patients under the Medicare and Medicaid programs who become "meaningful users" of certified EHR technology.¹⁴

¹⁴ To be a "meaningful user" of certified EHR technology, an eligible professional must demonstrate use of EHR technology in a manner which provides "for the electronic exchange of health information to improve the quality of health care, such as promoting care coordination". The use of electronic prescribing is also an indicator of meaningful use, and each professional must submit a report on their use of EHR meeting prescribed requirements: §1401(a). For the proposed definition of "meaningful use" issued by the Centers for Medicare and Medicaid Services, see: "CMS Proposes Definition of Meaningful Use of Certified Electronic Health Records (EHR) Technology", at: <u>http://www.cms.hhs.gov/apps/media/press/factsheet.asp?</u> <u>Counter=3564.</u>

Medicare: For eligible health professionals practicing under the Medicare program, the incentive payments are based on the value of the Medicare-covered professional services provided each year. The legislation rewards early adopters: a health professional can qualify for a maximum incentive payment of \$18,000 if they become "meaningful users" in 2011 or in 2012, but the incentive payment reduces each year; no payments can be made <u>after five years</u>, or <u>after 2016</u>, or for someone who adopts certified EHR technology for the first time <u>after 2014</u>.¹⁵ The legislation includes **penalties** as well as incentives. From 2015, a discount applies to the Medicare fee schedule for professional services, in respect of eligible professionals who are not meaningful users.¹⁶

For eligible hospitals, incentive payments begin with a base payment of US\$2 million based on a complicated formula that includes numbers of discharges, and the share of bed-days attributable to Medicare-financed services. Payments are reduced each year and ceased altogether <u>after four years</u>. No payments are made for hospitals that become meaningful EHR users <u>after 2015</u> so again, the legislation rewards early adopters of standards certified by the Secretary of Health and Human Services.¹⁷ Penalties also apply for hospitals that are not "meaningful EHR users" in 2015.¹⁸

Medicaid: The legislation also provides for federally-funded payment incentives to eligible professionals who meet minimum requirements in terms of patient volume in treating low-income patients under the Medicaid program, which is administered by each State. The incentive payments cover the cost of purchase, implementation and maintenance of certified

¹⁶ Ibid., §1401(b); 123 Stat. 115, 472. The discount is 1% in 2015, 2% in 2016, 3% in 2017. From 2018, the discount increases to 5% if the Secretary finds that less than 75% of eligible professionals are "meaningful EHR users".

¹⁷ Ibid., §4102; 123 Stat. 115, 477.

¹⁸ Ibid., §4102(b); 123 stat. 115, 482.

¹⁵ American Recovery and Reinvestment Act of 2009, Public Law 111-5 (February 17, 2009): Title IV Medicare and Medicaid Health Information Technology, §4101; 123 Stat. 115, 467, at: <u>http://www.gpo.gov/fdsys/pkg/PLAW-111publ5/content-detail.html.</u>

EHR technology.¹⁹ Children's hospitals, and acute care hospitals with 10% of patient volume comprising Medicaid patients also qualify. Eligible professionals may not receive both Medicare and Medicaid incentives during the same year.

As these examples show, developed countries are investing in a range of processes, structures and strategies to advance their e-health agendas. These approaches may also be relevant in developing countries. Depending on the level of development of the country engaged in e-health reform, however, the implementation of each strategy will also call for international collaboration with funders and development partners. This is an additional source of complexity!²⁰

If the goal is to achieve interoperability, for example, then the functions that the National e-Health Transition Authority performs in Australia will need to be replicated through the expertise and collaboration of funders and development partners with the national government.

Figure 5 summarises a country-focused approach to planning for e-health services. Rather than being dazzled by the possibilities of technology, e-health will have the greatest impact where governments and development partners prioritise planning towards those e-health capabilities and services that will help them to serve the unmet, priority health needs of the population.

The implementation of an e-health strategy is a complex national project. I believe there would be value in sharing experience of both the governance mechanisms that formed a part of successfully implemented e-health strategies, as well as the respective contributions and mechanics of collaboration between governments, development partners, funders and private sector stakeholders in realizing those national strategies.

²⁰ For discussion of guiding principles to assist governments, see John D. Halamka, "Making Smart Investments in Health Information Technology: Core Principles" *Health Affairs* 2009; **28, no. 2:** w385-w389.

¹⁹ Ibid., §4201; 123 Stat. 115, 489. Eligible professionals include physicians, dentists, certified nurse mid-wives, and nurse practitioners. Professionals must practice in a non-hospital setting with a minimum 30% of patient volume coming from Medicaid patients. For pediatricians, minimum volume requirement is 20%.

FIGURE 5: PLANNING FOR ICT IN HEALTH DEVELOPMENT

	Steps in the planning process	Characterising the nature of the challenge
1	Identify priority unmet health needs Adopt rigorous, country-centred approach ↓↓↓	Seek advice from epidemiologists; global and country health experts
2	In meeting these needs, what kinds of health care services & public health functions (eg improving maternal & pediatric health; diagnosis & treatment in the field etc) could be discharged more effectively with specific e-health services, capabilities, products?	 Calls for close collaboration between 1) governments and policy- makers; 2) health experts; 3) experts in ICT/e-health
3	Planning to finance, implement and thereafter to sustain the infrastructure & e-health services required to provide those services; discharge those functions	Frequently an international governance challenge involving governments, development partners and donors

TIER 3 REGULATION: HEALTH ICT AND CITIZEN PROTECTION

In developed countries, two enormous challenges loom constantly in discussion about electronic health records and telehealth: privacy, and liability.

PRIVACY

The right to privacy is an international human right protected in the *International Covenant on Civil and Political Rights*,²¹ the Universal Declaration on Human Rights,²² in regional instruments, and in many national constitutions.

²¹ International Covenant on Civil and Political Rights (1966), Article 17, at: <u>http://www2.ohchr.org/english/law/ccpr.htm</u>

 ²² Universal Declaration on Human Rights, UN General Assembly, Paris,
 10 December 1948, Article 12, at: <u>http://www.ohchr.org/EN/UDHR/Pages/</u>
 <u>Introduction.aspx</u>

The core of privacy legislation in OECD countries is the OECD Guidelines on the Protection of Privacy and Transborder Data Flows.²³ Privacy legislation imposes constraints on the way that organizations collect a person's identifiable health information. The right of a person to access their own health information is a large issue, as is the security of storage and transmission. Privacy principles and laws also regulate the purposes for which health information can be used, and to whom it can be disclosed.²⁴

The privacy and confidentiality of health information is frequently protected by privacy principles that are administered by a Privacy Commissioner. In addition, most legal systems have a range of criminal offences for intercepting telecommunications systems, and for unlawful disclosure of health information. The ethical and legal duty of confidentiality owed by a medical practitioner addresses the element of "disclosure" in privacy regulation.

Figure 6 summarises some of the common fears about how electronic health records will lead to a loss of privacy.

²³ OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data, 23 September 1980, at: <u>http://www.oecd.org/document/18/</u> 0,3343,en 2649 34255 1815186 1 1 1 1,00.html

²⁴ See, for example, the National Privacy Principles (NPPs) that apply to private sector organizations in Australia: <u>http://www.privacy.gov.au/</u><u>materials/types/infosheets/view/6583</u>

FIGURE 6: SOME COMMON CONCERNS ABOUT PRIVACY AND ELECTRONIC HEALTH RECORDS (EHRS)^

- Inability of consumers to opt-out of EHRs
- Inadequate constraints upon the collection, use and disclosure of patient health information
- Use of health data for inappropriate "secondary" purposes (ie purposes other than for which it was lawfully collected)
- Use of health data, over time, for new purposes which are authorized ("function creep"). Examples include criminal law purposes, as a pre-condition to receipt of social security benefits etc
- Dramatic increase in number of health professionals with a potential right to access the EHR
- Risk of illegitimate access from "authenticated users" of the EHR system
- Inability to "quarantine" especially sensitive health information within the EHR, with additional restrictions on access; inability to have some information recorded off-line
- One act of unauthorized access to EHR system may compromise records of many people, and more data relating to each individual (cf. how the clumsiness and time-consuming nature of the paper-based system is a safeguard in itself)
- Fragmentation of control over data in a federated, networked, "multi-function" EHR system

[^]Drawn from R. Magnusson, "Data Linkage, Health Research and Privacy: Regulating Data Flows in Australia's Health Information System" *Sydney Law Review* 2002; 24: 1-55, at 44-46.

The emerging view in my own country (Australia) is that a national electronic health record will require specific enabling legislation, including privacy legislation, in order to identify the agency with clear responsibility for management of the EHR system, in order to specifically identify the permitted uses and disclosures of health information on EHR systems, and to ensure transparency and public trust.²⁵

²⁵ See National e-Health Transition Authority (NEHTA), *eHealth Record: Shaping the Future of Healthcare: Privacy Blueprint for the Individual Electronic Health Record,* 2008, p 3, at: <u>http://www.nehta.gov.au/</u> <u>connecting-australia/privacy ;</u> Australian Law Reform Commission, *For Your Information: Australian Privacy Law and Practice,* ALRC Report 108, Chapter 61 (Electronic Health Information Systems), at: <u>http://www.austlii.edu.au/au/</u> <u>other/alrc/publications/reports/108/</u>

Privacy protection raises a range of more specific issues: how all of these will be resolved as Australia moves towards EHRs is not entirely clear.²⁶ For example:

- Stakeholder consultations have demonstrated clear support for an "opt-in" system (*ensuring voluntary* participation in an EHR system), as well as for an audit function that would provide a data trail on who accessed the record.
- There is also clear support for "sensitivity labels" that would allow individuals to partition sensitive information within their electronic records. But how this feature would be implemented is not yet clear.
- The circumstances in which hospitals providing critical care could exercise an emergency over-ride in order to access on-line health data remains to be clarified.
- There is perpetual debate over the extent to which electronic health data should be made available for "secondary purposes" including research, and quality assurance functions.

Some may suggest that privacy is a distinctively "western notion", appropriate for high-income European democracies, but less suited to developing or non-western countries that emphasise the priority of the community, or the state, over the individual. It may well be true that consumer resistance to privacy-invasive schemes is higher in democratic countries with a libertarian tradition – to the point where some initiatives fail the public trust test and become politically non-viable. On the other hand, even in low income countries, there would appear to be areas of medicine – including HIV/AIDS, STIs, mental illness, drug dependency issues, and areas relating to reproductive health – where the persistence of stigma and discrimination points to the importance of privacy protection in order to create the conditions where individuals will trust their health providers, and come forward for treatment and advice.

Building e-health systems upon a secure foundation of privacy laws is likely to be an effective way of building trust and encouraging demand for the use of e-health services.

²⁶ See NEHTA, *Privacy Blueprint for the Individual Electronic Health Record: Report on Feedback*, 7 November 2008, at: <u>http://www.nehta.gov.au/</u> <u>connecting-australia/privacy</u>

One important aspect of privacy law in developed countries relates to controls over transborder data flows. In Australia, for example, an organization is prohibited from transferring personal information off-shore except to recipients who are legally bound to uphold substantially similar privacy standards.²⁷ Provisions like these – in developed countries – also carry implications for developing countries.

For example, partnerships between hospitals and health professionals in high income countries, and their counterparts in low income countries, play a central role in health development. The benefits of these relationships can be leveraged through e-health, particularly telemedicine and the use of ICT in training and capacity building.

Provisions requiring equivalent privacy protection for data received by health professionals in OECD countries – as a condition to transmitting it back to its source in a low income country – could become an obstacle to participation in trans-border e-health services by health professionals and organizations in developed countries. Even for purely pragmatic reasons, therefore, developing countries would be wise to plan for robust privacy protection in their e-health reform processes.

Furthermore, the digitisation of health care records opens up a range of opportunities for outsourcing of medical services from high income countries to professionals located within middle income countries (for example, teleradiology). Robust privacy protection in those middle income countries confers a competitive advantage.²⁸

²⁷ See the *Privacy Act* 1988 (Cth), Schedule 3 (National Privacy Principles) – Principle 9: Transborder Data Flows, at: <u>http://www.privacy.gov.au/law/act/npp</u> The OECD is continuing to study the issues faced by privacy agencies in cooperating across borders in the enforcement of privacy laws. See OECD, *OECD Recommendations on Cross-Border Co-operation in the Enforcement of Laws Protecting Privacy*, 12 June 2007, at: <u>http://www.oecd.org/documen t/25/0,3343,en 2649 34255 37571993 1 1 1,00.html</u>

²⁸ See Sanjiv N. Singh, Robert M Wachter, "Perspectives on Medical Outsourcing and Telemedicine – Rough Edges in a Flat World?" *New England Journal of Medicine* 2008; 358: 1622-1627. Although organizations that outsource medical services, including those operating within the United States, may insist on contractual duties to protect the privacy of data, contractors nevertheless operate "beyond the scope of direct supervision" (at 1623).

QUALITY AND LIABILITY

Quality is destined to become a central concern as countries increasingly practice telemedicine and implement other e-health services. On the one hand there are uncertainties about how the availability of expert, on-line clinical support systems (such as drug-dose and drug-interaction alerts) will **raise** the expectations of patients and thus the duty of care owed by physicians to their patients. On the other hand there are also concerns about the failure or malfunction of systems and resulting harm to patients.²⁹

Low income countries – as much as high income countries – have an interest in protecting patients from the risks of harm caused by inaccurate information and poor quality advice accessed on-line, as well as from the practice of "cybermedicine" by unqualified and incompetent professionals, and other opportunists.

At the national level, countries protect their populations by imposing registration and licensing requirements upon those who wish to practice medicine. A unified, national approach to registration is a pre-requisite to telemedicine and national interoperability in a federal system.

In Australia, for example, cross-jurisdictional workforce mobility as well as public safety has been enhanced by a single national registration and accreditation scheme that (1) establishes national registration Boards covering ten health professions and (2) eliminates the duplication of regulation in

²⁹ For a review of e-health liability issues, see: Sharona Hoffman, Andy Podgurski, "E-Health Hazards: Provider Liability and Electronic Health Records Systems", Case Western Reserve University School of Law, Working Paper 09-25, August 2009, at: <u>http://ssrn.com/abstract=1463671</u>

each State.³⁰ National registration systems can also enhance public health by providing for the deregistration of a health professional who, for good cause, has been deregistered in another state or province, or in a foreign jurisdiction.³¹ Arrangements like this make sense in all countries that are developing national e-health capabilities.

Increasingly, quality issues in e-health have an international dimension, due to the expansion of international telemedicine and the international outsourcing of medical functions.

For example, health institutions in high income countries which outsource teleradiology to countries with favourable time zones or cheaper labour costs face novel issues about the liability of their home institution for medical errors made by

³¹ See, for example, in New South Wales, *Medical Practice Act* 1992 (NSW) ss 31-35. These provisions give the New South Wales Medical Board the power to de-register a person registered in NSW (but de-registered under a foreign law) for reasons relating to professional misconduct or physical or mental capacity to practice medicine (s. 32). Note that from 1 July 2010, the NSW Medical Board will become a committee of the single, national, Medical Board of Australia.

³⁰ The new scheme is regulated by the Australian Health Practitioner Regulation Agency: <u>http://www.ahpra.gov.au/</u> Health practitioner regulation has hither to been a function of each State and Territory. In order to create a unified, national scheme, each State and Territory is successively passing legislation adopting the "Health Practitioner Regulation National Law" as a law of that jurisdiction: see, eg, Health Practitioner Regulation Act 2009 (NSW). The "Health Practitioner Regulation National Law" was originally passed by the Parliament of Queensland (with other jurisdictions adopting that law). For further discussion, see: Intergovernmental Agreement for a National Registration and Accreditation Scheme for the Health Professions, 26 March 2009, at: http://www.nhwt.gov.au/documents/ National%20Registration%20and%20Accreditation/NATREG%20-%20 Intergovernmental%20Agreement.pdf; Australian Health Ministers' Advisory Council, Regulatory Impact Statement for the Decision to Implement the Health Practitioner Regulation National Law, 3 September 2009, at: http:// www.nhwt.gov.au/documents/National%20Registration%20and%20 Accreditation/Regulatory%20Impact%20Statement%20for%20the%20 decision%20to%20implement%20the%20Health%20Practitioner%20 Regulation%20National%20Law.pdf

foreign contractors, or for technology failures during transmission.³²

Legislatures or professional associations may also restrict or regulate the credentials of foreign radiologists by requiring registration in the country, or in the state, where the patient lives and the report is to be provided. The American College of Radiologists, for example, states that:

"physicians who interpret images by teleradiology shall (1) be licensed to practice medicine in the state where the imaging examination is originally obtained... (2) be credentialed as a provider and maintain appropriate privileges in the health facility or hospital in the United States where the examination was obtained; (3) have appropriate medical liability coverage for the state in which the examination was obtained; and (4) be responsible for the quality of the images being interpreted".³³

The context is somewhat different when it comes to health care organizations and professionals in high income countries providing services (as partners in health development) to organizations and patients within a low income country.

For example, a few months ago I was asked about the potential liability of a children's hospital in Sydney if its employed physicians caused harm by giving incorrect advice about poisons or toxins to colleagues at a children's hospital in a regional area in a south east asian country. As far as I know, the domestic laws of that country do not demand local registration for international experts dealing with patient issues

³³ American College of Radiologists, "Revised Statement on the Interpretation of Radiology Images Outside the United States", 23 May 2006, at: <u>http:// www.acr.org/SecondaryMainMenuCategories/BusinessPracticeIssues/</u> <u>Teleradiology.aspx</u>

³² Sanjiv N. Singh, Robert M Wachter, above n. 28. See also J. Thrall, "Teleradiology: Two-Edged Sword or Friend of Radiology Practice? *Journal of the American College of Radiology* 2009; 6: 73-75. Singh and Watcher argue, for example, that an entity organizing teleradiology may be liable "for a variety of breaches related to the mechanism of outsourcing itself – for example, for ghosting, failure to supervise, and failure to ensure appropriate licensure – even if the remote provider is not found to be individually liable" (at 1624).

through telemedicine. Nor would there be any realistic prospect of a lawsuit against an Australian physician, even if a patient were harmed following a medical error.

Nevertheless, the Australian hospital was concerned about the scope of coverage of the indemnity insurance covering the acts of its physicians.

In project-based development work, general insurance, public liability and professional indemnity insurance will routinely be built into the cost of project funding.

It is also possible that liability issues could be resolved by formal agreements between health care organizations in each country. Nevertheless, even as health ICT permits the formation of collaborative networks extending across borders (with physicians in high income countries perhaps acting as mentors to colleagues in low income countries) there is the prospect that liability concerns and contractual constraints could become a brake on these forms of collaboration.

I do not have any easy answers to this issue. Is it ethical for a health care organisation in a high income country to insist on "all care, no responsibility" as the price for the involvement of its employees in cross-border telemedicine?

Developing countries need forms of regulation that will keep the charlatans out of e-health, while encouraging the institutional contacts that e-health makes possible with partner institutions in developed countries – which could be immensely valuable.

FRAUD AND DECEPTION

Fraud, and misleading and deceptive conduct as they relate to health products and services are not new problems created by e-health. They are, nevertheless, problems that have the potential to thrive in the borderless telecommunications environment. In many developed countries, the proliferation of health content of variable quality, and the difficulty that consumers have in judging quality, has led to "trusted agencies" setting up websites offering basic advice and links.³⁴

³⁴ For example, Medline Plus, a service of the U.S. National Library of Medicine and the National Institutes of Health, at: <u>http://medlineplus.gov/</u>. Similarly, see HealthInsite, an Australian government initiative: <u>http://www.healthinsite.gov.au/</u>

In Australia, misleading and deceptive conduct in the health sector, or in relation to health products and services, is subject to investigation and prosecution by the Australian Competition and Consumer Commission (ACCC).³⁵ In the United States, the Federal Trade Commission plays an equivalent role.³⁶ Legislation also creates criminal offences for the use of misleading titles, including for passing oneself off as a registered medical practitioner.³⁷

There is no magic bullet for the use of telecommunications services to *deceive across national* borders, other than closer cooperation in investigation and enforcement by national consumer protection agencies.³⁸

RECOMMENDATIONS

This rudimentary survey of legal and governance issues in e-health leads to two recommendations. Firstly, WHO and the Health Metrics Network might consider sponsoring a more detailed analysis of the kinds of governance issues (including legal and ethical issues) that developing countries face as they develop e-health strategies.

Secondly, as stated above, it will be important to identify those strategies in developed countries that underpin success in implementing e-health strategies and to consider how, with collaboration from development partners, developing countries can implement equivalent strategies.

³⁵ Constant vigilance by national consumer protection agencies is required. See ACCC website, at: <u>http://www.accc.gov.au/content/index.phtml/</u> <u>itemld/5967</u> See also ACCC, "Fair Treatment – Summary of the Guide to the *Trade Practices* Act 1974 for the Advertising or Promotion of Medical and Health Services", 31 July 2000, at: <u>http://www.accc.gov.au/content/index.</u> <u>phtml/itemld/309076.</u>

³⁶ See the Federal Trade Commission website at: <u>http://www.ftc.gov/bcp/</u> <u>menus/consumer/health.shtm</u>

³⁷ For example, in New South Wales, *Medical Practice Act* 1992 (NSW) ss. 105-110, at: <u>http://portsea.austlii.edu.au/cgi-pit/maketoc.py?skel=/home/</u><u>www/pit/xml/nsw/act/nswA1992-94_skel.xml&date=</u>

³⁸ See OECD, OECD *Guidelines for Protecting Consumers from Fraudulent and Deceptive Commercial Practices Across Borders*, 11 June 2003, at: <u>http://www.oecd.org/document/50/0,3343,en 2649 34267 2514994 1 1</u> <u>1 1,00.html</u>
Ľ.	ublic Law 111-5-Feb. 17, 2009], at: <u>http://www.gpo.gov/fdsys/pkg/PLAW-111publ5/content-detail.html</u>
	Tier 2 - e-health reform: specific initiatives
	Establishes Office of the National Coordinator for Health Information Technology (within Department of Health & Human Services).
	Functions include:
	 Reviewing and endorsing standards and specifications for e-exchange of health information Maintain federal health IT strategic plan
	 National Coordinator to prepare report identifying lessons learned by major public & private health care systems in their implementation of health ICT
	 Identify practices to increase adoption of health ICT serving under-privileged communities
	 HIT Policy Committee to make policy recommendations to National Coordinator
	 HIT Standards Committee to recommend standards, specifications to National Coordinator
	Requires:
	 Federal agencies to use health ICT systems that meet standards and specifications adopted by the Secretary of Health
	and Human Services, and to require the use of approved standards and specifications in contracts relating to federally
	administered or sponsored health care programs
	 Secretary to report to congressional committees on actions by federal government and private entities to facilitate
	implementation of nationwide system for electronic exchange of health information, including barriers to adoption and recommendations
	 Secretary to invest funds through appropriate agencies to support a national system of electronic health records and
	electronic exchange of health information. Secretary may also make grants to States and to State-approved entities.
	 Secretary to create a Health Information Technology Research Center to provide technical assistance, and to develop best
	practices for health ICT
	Provides for:
	Medicare incentives: Incentive payments to eligible professionals and hospitals who demonstrate that they are "meaningful
	users" of certified EHR technology. Legislation rewards early adopters; payments phased out over maximum period of five
	years, and four years, respectively. Beginning in 2015, penalties apply for hospitals that are not meaningful EHR users.
	 Medicaid incentives: Federally-funded incentives payable through state-administered Medicaid programs to support
	purchase, implementation and maintenance of certified EHR technology

APPENDIX A: Selected e-health governance initiatives from the American Recovery and Reinvestment Act of 2009

REVISITING HEALTH INFORMATION AND EHEALTH POLICIES AND GOVERNANCE STRUCTURES IN AN INCREASINGLY COMPLEX ENVIRONMENT

PATRICIA MECHAEL eHEALTH CONSULTANT THE ROCKEFELLER FOUNDATION

PRESENTED BY KARL BROWN

As a sector, health is information driven, whether it is improving health outcomes, access to health, quality of health, financing for health, health promotion, or other aspects of ensuring that those in good health remain healthy and those in need of diagnostic and treatment support receive the best guality care in a timely and cost-effective fashion. For the past 10 years, health information policies have largely emerged in tandem with the strategic use of technology solutions to capture and move information in a more efficient, effective, and cost-beneficial manner. In low and middle income countries, such policies and systems have primarily focused on the handling of aggregated data in the public health system through District Health Information Systems from the district level to the regional level to the national level. With increasing spread of telecommunications infrastructure through mobile phone networks, satellite technology, and fixed broadband cable extensions- additional e- and mHealth solutions are significantly increasing the information generated, the number of public and private sector health sector and technology solutions actors, and the reach to sub-districts, communities, and individuals. With the proliferation of mobile telephony and mobile broadband the potential increase in data flow is exponential.

Understanding the challenges that countries face when developing policies and guidelines for these categories of eHealth within a broader health information system framework is critical for ensuring efficient and effective information flows that will ultimately result in better health outcomes and related decision making. With the increase in cloud computing and networking, questions regarding data storage, security, and transmission arise. Health information policies are largely developed and implemented by Ministries of Health; however, they are influenced and impacted by a country's National Information Policy, eGovernment Policy, and eHealth Policy.

POLICIES THAT IMPACT HEALTH INFORMATION POLICIES

- National Information Policy: Framework and approach governing a wide range of aspects regarding national information. Issues such as quality of information, access, legal deposit, intellectual property, freedom of information, data protection, and privacy. This type of strategy is comprehensive and applicable across sectors.
- National eGovernment Policy: A framework and approach for incorporating ICT across governmental sectors (e.g. health, education, welfare etc.)
- National eHealth Policy: Framework and approach for developing eHealth in a country, established by the government with the intent of achieving health goals. Increasingly guidelines for mHealth initiatives are being integrated into eHealth policies

HEALTH INFORMATION STRATEGIC PLAN: THE CASE OF GHANA

In a recent landscape of the health information and eHealth policy environment in Ghana conducted for the Rockefeller Foundation, it was noted health is indicated as a priority sectoral focus area within ICT and eGovernment policies and the use of ICTs and better information and communication management is indicated within health policy framework documents. The challenge, however, is translation of plans and policies into operational, interoperable, scalable, sustainable, costed systems with responsibilities assigned to the appropriate agencies and accountability to ensure fulfillment of planned activities.

The MOH of Ghana has published in its Health Information Strategic Plan for 2007 to 2011 its overall goal set for its health information system "to make reliable health information available for decision-making". For the medium term, four strategic objectives have been identified:

- 1. to improve the environment for health information management
- 2. to improve the capacity for managing health information at all levels

- 3. to improve quality of information generated by the health sector
- 4. to improve the use of information for decision making

As indicated earlier, the MOH in Ghana also develops a series called the Health Sector 5-year Programmes of Work, and within the most recently made available program for 2007-2011, health information systems have been mentioned several times as key priority activities. More specifically, for health information management, key priority activities are:

- 1. Implement the health sector ICT policy and strategy
- 2. Develop and implement a strategic plan for National Health Management Information System including a link between financial management and service delivery information
- 3. Strengthen demographic surveillance sites and communitybased surveillance systems
- 4. Scale up the district wide system for information management to ensure the availability of accurate and reliable routine service based data
- 5. Improve management of and access to health information

Considerations need to be made for how to effectively integrate and use data currently being produced through a broad range of mechanisms and systems. To help make sense and provide an overarching framework for existing and planned eHealth systems, the GHS has drafted an eHealth Enterprise Architecture, which is currently under review.

HMIS ARCHITECTURE AND COMPONENTS



System component System function

GOVERNANCE: THE NEED FOR NEUTRAL LEADERSHIP AND GUIDELINES

A key influencing factor in the development of such policies and how effective they become is funding, namely who is paying for and/or providing such services. With large-scale publicly-funded health information systems, more control over implementation and application of policies rests within the government. With increasing implementation of health information-generating systems across public systems, including the MoH and NationalHealthInsuranceSystemdevelopment,coordination,and accountability for adherence to policies becomes more complex. In addition, private sector investment, including foundations, multi-national and national telecommunications and health IT companies constitute a growing body within the health information ecosystem. Stewardship over health information policies is largely dependent on the governance structures in place to set and manage policies and legislation. In order to provide neutral coordination across institutions representative bodies that sit outside of the government or in the president's office are increasingly being established with the aims of increasing:

- Accountability: Public health officials to be answerable to public for government actions
- Participation: Involvement of citizens, private sector and other stakeholders in planning
- Consistency: Equitable and consistent application of policies and legislation relating to health
- Transparency: Making information on policies, regulations, and decisions available to public

Governance policies are essential to ensure successful collaboration amongst stakeholders, which are crucial to the success of implemented programs.

SYSTEMS INTEGRATION: MOVEMENT TOWARDS INTEROPERABLE SCALABLE SOLUTIONS

To date, many of the electronic health information systems that have been implemented are stand-alone silo-ed systems. With the introduction of mobile technology inputs into district health information systems and the increasing numbers of other eHealth systems (telemedicine, mHealth, electronic medical records, emergency response, disease surveillance, insurance payments management, etc.), greater attention is being drawn to the need for enterprise architectures based on open interoperable standards. To this end, having clearly a defined eHealth Strategy will enable both public and private sector players to contribute to a common set of pre-identified goals, objectives, and standards- both in terms of technology but also in terms of terminology and reporting.

In the effort to scale electronic health information and other eHealth systems beyond districts to community level and vice versa, the issue of infrastructure becomes critical. In order to engage in national eHealth systems, connectivity, electricity, and the necessary hardware and software needed to increase systems coverage. In this regard, governments should begin to explore mutually beneficial partnerships with telecommunications industry partners and nongovernmental partners, such as the private sector, aid agencies or other bodies to promote infrastructure development and universal access. A plan or "technology road map" that outlines the national deployment and development of ICT infrastructure and services should prioritize access to infrastructure to support the health sector. Governments should also work with industry partners to reduce the costs of ICT infrastructure for the health sector, for example of computing equipment, software, Internetinaddition to fixed pricing for data and/or communications services.

In order to promote learning on what works and how it works, greater focus is needed on evaluation and research to fully appreciate the impact of health information and eHealth systems so that they can be appropriately budgeted for and scaled up in a way that does not burden governments or health professionals. To this end, mechanisms and systems to evaluate the impact of such systems on health care management, health outcomes, clinical effectiveness, and knowledge and behaviours among providers and clients. Partnerships with academic institutions should be fostered to establish baselines and integrate monitoring and evaluation systems to inform future programming and scale as well as to contribute to the growing evidence base on health information systems and eHealth.

PUTTING PEOPLE FIRST: SUPPORTING CITIZENS AND HEALTH PROFESSIONALS

Discussions surrounding health information policies have largely dealt with aggregated information. As systems move towards more individually based information for citizens and health professionals, new policies are needed to address citizen protection, equity, and capacity to capitalize on access to new technologies as well as to information. With increasing individual level data governments will need to implement regulations and legislation to protect the privacy and security of individual patient data. For services delivered through electronic means as in the case of telemedicine, guidelines and policies to ensure consent and address issues of liability will need to be developed. In terms of equity, policies that promote inclusiveness and equitable access to eHealth irrespective of culture, education, language, geographical location, physical and mental ability, age, and gender are needed so that those who stand to benefit the most of eHealth are not excluded from it. While health information is often ported and adapted from one country context to another, efforts should be made to promote the availability of information in local languages that recognize cultural diversity in addition to translation and cultural adaptation (localization) of existing high-guality content created either locally or abroad.

A major challenge in the design and implementation of health information systems is human capacity to engage users in participatory design processes, process and provide feedback on data in a timely fashion, integrate information into existing workflows and day to day routines to improve decision making and service quality, and to make the most effective use of tools and solutions deployed to generate, capture, process, and report on health-related data. Existing curricula for health professionals need to be re-examined in light of the digitization of many health-related processes and information. For those already in the health care workforce, continuing education modules in health information management, basic ICT skills, and the use of eHealth solutions are needed at all levels. In addition, universities and governments should consider the development of a multi-disciplinary and multi-faculty educational program and career track for those who can help liaise between the health and ICT sectors to design, develop, implement, and train individuals in the use of health information and other eHealth systems.

CREATING AN ENABLING ENVIRONMENT

Countries throughout the world are at a critical juncture in their implementation of health information and eHealth systems, where the complexities of the environment are continuing to increase and evolve. While policies and strategies are helpful for guiding institutions in positioning health information and eHealth systems, they are only as good as the governance bodies setting, operationalizing, and providing oversight for policies and legislation. In addition, there are systems and human considerations that must be addressed including interoperability, infrastructure deployment, metrics and evaluation, ethical aspects of health information, and capacity to capitalize on such systems. At the global level, there is a need to collate learning and establish flexible guidelines that can be adapted at the national level to the local context for organizational leadership and governance, systems design and integration, clinical standards and outcomes metrics, and supporting citizens and human resources for health- to promote the development of effective policies and legislation in this area. Such efforts should first and foremost be predicated on meeting a country's health priorities, objectives, and targets.

POLICY AND TECHNOLOGY IN HEALTH INFORMATION SYSTEMS

ERIC RASMUSSEN CHIEF EXECUTIVE OFFICER INSTEDD

A CAUTIONARY TALE: THE SWAT EMERGENCY

Pakistan's northern Swat Valley was the site of a massive humanitarian emergency in April and May of 2009. Over a period of two months, more than 2 million people were uprooted from their homes by violence between the Taliban and the Government of Pakistan. Hundreds of civilians were killed, thousands were injured, and thousands more became ill. Rough estimates from area health care providers indicated 60,000 pregnancies within the displacement, most of them kept invisible to outsiders.

The May 2009 International Medical Corps (IMC) assessment of the displaced populations fleeing the Swat Valley Emergency noted that nearly 90% of the more than 2,000,000 displaced had been absorbed into host communities and not into traditional displacement camps. That made them extremely difficult to support through conventional camp-based health services and mandated the urgent development of a regional health information system to manage injury, illness, and Maternal-Child Health in a rural population under acute stress. That effort was severely under-resourced and regrettably incomplete.

By mid-summer 2009, basic services such as health, education, water and sanitation were stretched to the breaking point throughout north-central Pakistan. By the end of the summer humanitarian aid agencies had seen outbreaks of waterborne diseases, acute malnutrition, and increased childhood deaths from diarrhea and exposure. In August there were anecdotal reports of a significant increase in maternal deaths from complicated childbirth, and International Medical Corps reported patients presenting with untreated and suppurating war wounds, uncontrolled diarrhea, multiple skin and intestinal parasites, and severe respiratory infections. The Red Cross Hospital in Peshawar overflowed for weeks with traumatic injuries from burns, blast overpressure, penetrating projectiles, and blunt trauma. Some injury management and supplemental feeding requirements still remain in January 2010.

This unexpected war-driven migration, with more than a million internally displaced and disappearing into local homes, made every bit of health information vital. Putting that information together into a coherent picture was a frustrating piecemeal effort made more challenging by scant resources and poor infrastructure. Some clinics, both Pakistani and international, were known to have exhausted their medical supplies by late May, but no one was guite sure which clinics, or who they were serving, or where those patients went as a result. In that acute crisis the accurate flow and management of health information in areas below the Swat Valley became a critical lifesaving need, yet there were multiple impediments to its collection, consolidation, analysis, and subsequent dissemination. The health information impediments were technical, political, ethical, religious, logistical, and legal, yet all are manageable, and each could have been addressed effectively within a useful timeframe given adequate resources and the political will.

It is reasonable to state that, as a consequence of these inefficiencies, suffering was extended and lives were needlessly lost. The urgency of this crisis, and the critical role technology and policy should have played in the movement of information, is worth noting. It's an example of technology and policy around a weak health information infrastructure falling short when routine requirements are acutely expanded by unexpected events. No resilience.

HEALTH INFORMATION TECHNOLOGY: MHEALTH

The remainder of this brief essay will address only mHealth in the context of technology and policy, with the Swat Valley example in mind. A longer discussion on broader health information system topics elsewhere would be welcomed.

At this Global Health Information Forum we have a remarkable collection of people. We are a tiny slice of the global population, yet our proposed 2010 Call to Action might, over the next five years, touch the lives of more than 3 billion people. Here in Bangkok, at PMAC, we have a critical mass of those designing and funding health information systems (HIS) for the developing world, incorporating efforts in eHealth and mHealth. Those two subsets of HIS are areas of particular interest to InSTEDD. InSTEDD, as many of you know, is an NGO committed to the harnessing of technology for effective collaboration against global health threats. For us, mHealth systems, particularly in biosurveillance, distributed patient management, and outbreak response coordination, are already a critical part of our everyday work around the world.

Fortunately, it is fair to state that, as a community of practice, we've all moved quite far down the road toward an effective mHealth platform. Our collective ideas are perhaps not yet as flexible as we'd like them to be, or as integrated, or as standardized, or as secure, or as resilient with low-density languages, or as forgiving of illiteracy, but we at least now know that each of those core issues exist and that we need to work on them.

Together, around the subject of mHealth, we've generated significant body of work and, frankly, we've generated excitement at the potential for doing so much good for vulnerable populations who have few resources beyond a mobile phone. Many of us are ready to scale our work from pilot studies to robust and flexible architectural components that reflect the needs we've found with users on the ground. We're ready to move forward. And we should hurry, for several reasons.

ECOMMERCE AND MSENSORS

One reason is the medical issues we face. Let's look at just one number for a single emerging infectious disease in a single remote location: Tajikistan, a small Central Asian state north of Afghanistan. In late 2008 the percentage of new tuberculosis cases that were multi-drug-resistant there was 14%. That is roughly one in seven, a year ago. Now, in December 2009, that caseload for MDR-TB has increased to 23%, or almost one in four. That is a concerning increase in very worrisome disease in remote little Tajikistan, a place that is not equipped to handle that disease burden. Better health information management there is already a critical, and unmet, requirement.

Another reason we should hurry is the speed of technological advance in phones. We are already behind what our patient populations expect us to be able to do. A 2009 article in New Scientist makes the point that here in mHealth, we are just barely ahead of an oncoming train in mobile services. In that article author Linda Geddes notes that we are perhaps four years from ubiquitous mCommerce, with financial transactions as common, and as easy, over the phone as they are now over the web. We all recognize that money is routinely transferred by mobile phones in Afghanistan, the Philippines, East Africa and elsewhere, and that tickets for trains and airlines can be bought on phones with a few keystrokes in Japan.

Now Nokia and others are evaluating biometric sensors for cellphones that not only measure simple vital signs like pulse and blood pressure, but also have more sophisticated capabilities like pulse oximetry, glucose monitoring through fingertip touch, chemistry assessments through saliva sensors and breath analyzers, and more.

MICRO-EVERYTHING: MX DRIVEN BY THE MARKET

And on a very related topic, Kazi Islam, director of IT at Grameen Phone in Bangladesh describes the efforts already underway with a California company, Obopay, for microbanking in the slums of India. He has also mentions initiatives with other companies to provide micro-insurance for cows, fish farms, bicycles, and other small, important possessions at risk in a disease outbreak or a natural disaster, or during other events leading to social disruption. Now, along those micro-insurance lines, Natchiket Mor of ICCC in India is leading one of several efforts underway to provide health insurance to the poor. He's currently charging 2 (two) US dollars per month for a family of four in rural India, paid by mobile phone, with appointments by mobile phone. Vaccinations are included.

MECONOMICS AND A SOCIAL BUSINESS

From a holistic perspective, two these two cellphone tools, micro-banking and micro-insurance, are becoming critical satellite components in the provisioning of effective Health Information Systems. They are the foundation of personal safety nets and often designed on a model from the Nobel Peace Prize speech of Mohammed Yunus in which he described the concept of a "social business." A social business is a method of ensuring economic sustainability though a business plan that pays no dividend, but also results in no loss. The social business method keeps many people employed sustainably, but without substantial profit and with only modest risk. That might be an excellent model for building a system of healthcare for vulnerable populations and it is, more or less, what's being done in India. The mHealth concept seems to have the capacity to implement that sustainable economic model more effectively than any other proposed long-term method. Other possibilities

might include a for-profit model, a faith-based model (sustained by sectarian donations), a tax-based governmental model, a Foundation based system, and there are more. When mHealth is coupled with micro-banking and micro-insurance, though, InSTEDD sees the potential for a robust and resilient community-level model for poverty alleviation and health improvements through closely interlinked mobile strategies.

RISKS IN DEVELOPMENT

While mHealth models can approach financial stability using these economic tools, we can see a different sort of risk in the implementation of mHealth software tools. At InSTEDD we see a software development community of practice at risk of partitioning, of fractionalized efforts, of non-standard coding and interaction, and of such frustrating inefficiency across boundaries that mHealth adoption suffers, donor dollars are used inefficiently, and, as perhaps second or third order effects, patients die needlessly. These are serious mistakes that are completely avoidable and that we should be correcting now. This week.

IF YOU DON'T GO, YOU DON'T KNOW

Please let me offer a word on donor dollars. My organization, InSTEDD, lives off of them, as do many others here at the Conference. Whether it's Rockefeller, or Gates, or Google, or DFID or USAID, or GTZ, or the UN, or the World Bank, or anyone else granting money to the improving of health systems in the developing world, donors have a responsibility and an opportunity that is not yet fully recognized.

A few lines of background: When I started InSTEDD we developed a few core principles within the organization, one of which was that our implementation metrics were to be measured as close to the people we were serving as possible. Another was that we would work side-by-side with our users, to ensure that what we were developing genuinely answered their needs. We also determined that we'd establish a long-term presence wherever we worked, answerable every day for the work that we did there and training local staff to take full ownership of the tools we built with them. We would learn as much as we taught and we would build a local brain trust around free, open source, highly competent, deeply relevant tools built to do whatever our health partners say they need, starting with their bedrock-simple 2G mobile phones. We are also agnostic in using the right tool for the task we see required; we only build tools when we perceive a gap, and so we use open-source software, both mobile and web, from other organizations without hesitation and with genuine admiration. That approach is not particularly sexy, and it is almost invisible, but it's apparently been useful and rewarding for those health professionals working in partnership with us inside the Mekong Basin Disease Surveillance (MBDS) network.

A DONOR CHALLENGE

I note, though, that the architecture of global development funding is often not conducive to organizations like ours working together with other NGOs to inspire open-source social-change health infrastructure solutions. We instead sometimes find ourselves competing against each other inappropriately by the nature of the grant-making process.

We can all do better than that. As we might expect, some of the first-generation tools for mHealth were closed proprietary systems that do not interoperate. Those mHealth tools may share features, but not the underlying code that would allow health ministries to ensure the information is secure, yet readable, across all of the places they need to use it. Those non-standard systems store and transport data using unique protocols and formats, making communication across platforms very challenging. As a result, applications are difficult to integrate, localize, or adapt to a new purpose.

I'm here advocating for a better method. I think there should be a new model of donor responsibility. I suggest for consideration that the major donors in mHealth form an Alliance among themselves, then set a policy of open standards, standards that make sense now and into the future for interoperability across the continuum of medical care. Those open standards can be determined by a Technical Advisory Group like the Open Mobile Consortium, and InSTEDD would volunteer to be a part of that engineering standards effort. Although I don't speak for them, I would also imagine that InSTEDD's existing partners, like OpenMRS, OpenROSA, DataDyne, ChangeFusion, Carl Taylor's group creating AIMS, the Health Metrics Network co-sponsoring this conference, and Chris Seebregts's group in South Africa would all be interested and there are probably many more. This should be a very achievable goal.

Once such standards are in place, I think that donors should

then gently pressure their grantees to form networks of partners, using competition dynamics if they're necessary, but supporting the mandates of collaboration, interoperability, open APIs and fostering the new techniques of "co-opetition". Coopetition is the idea that having multiple organizations working separately toward a common goal, using sharable components and mashable tools, makes the final system stronger, more flexible, and more resilient. At InSTEDD we've chosen to make our work free and open source, but that's not mandatory to meet open standards. What matters is interoperability when trying to achieve a critical task like healthcare delivery in our very challenging environments. Let's focus there.

This conference will expose a range of fascinating efforts in mHealth, eHealth, and the architecture of health information systems. We'll discuss medical record keeping, lab diagnostics, digital radiography, biosurveillance, HIV appointment management, STD surveys, TB DOTS verification and more, and they all deserve our attention. We know from these stories how hard the social, political, ethnic, legal, educational, financial, academic, and cultural issues can be. Let's now have the donor community do what they can to eliminate the stovepipes and silos that put technical impediments in our way as well. We need, in mHealth, open standards and impact metrics that award points for collegiality, moving everyone toward a common goal clearly rooted in the health of our patients. Having the donor community foster that spirit of shared success would be very welcome. We can then move more effectively into the political and regulatory efforts that will need to be our next steps.

THERE AND BACK AGAIN

Those next steps need to include an exit strategy that allows NGOs like mine to go home and leave the business of caring for the national population to the national government in every case where we can make it work. There are entire international industries developing around the management of health information that seem to usurp the necessary social contract between a central government and the population they should be serving. Particularly in nations where that relationship between citizens and their central authority is fragile, taking eventual responsibility for the health and safety of the citizenry is a natural and right obligation of the government. The acceptance of that responsibility needs to be seen by the people as a social good shouldered by their national leadership. We, as health informatics professionals, therefore need to ensure there is a clear transition to national autonomy built into our HIS implementations.

IN SUMMARY

I'm advocating those two tasks:

- 1. Donors begin driving interoperability as a condition of an HIS grant, and
- 2. Donors begin driving capacity building and exit strategies as a component of any HIS implementation.

Thank you for the opportunity to attend this conference.



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Karl Brown joined the Rockefeller Foundation in 2006. As Associate Director of Applied Technology, Brown is focused on the application of information technology to the programmatic work of the foundation. He is working on exploring and nurturing imaginative uses of technology by Rockefeller grantees, and improving collaboration and knowledge management within the Foundation.

Prior to joining the Rockefeller Foundation, Brown worked as the Chief Technical Officer of GNVC, an NGO that fostered entrepreneurship in Ghana. Previously, Brown was a technical team lead with Trilogy, where he developed and deployed enterprise systems and consumer-facing websites for Fortune 500 companies such as Ford and Nissan.

Brown received a Bachelor of Science in Computer Science from Stanford University and a Master of International Affairs from Columbia's School of International and Public Affairs.

B

MICHAEL GRAVEN

SENIOR ADVISOR OF HEALTH AFFAIRS GOVERNMENT OF BELIZE

Dr. Graven is a member of the faculty of Medicine at Dalhousie University in Halifax Nova Scotia, Canada. He is clinical Neonatologist, with board certification in Neonatal-Perinatal Medicine. He also teaches graduate students in the Medical Informatics Graduate School. He is a member of the Steering Committee of the Canadian Perinatal Surveillance System, which is a part of the Federal Public Health Agency of Canada. He also is a member of the Executive Committee of the Medical Informatics Program at Dalhousie University. Dr Graven is also a Fellow of the WHO International Collaborative Center for Reproductive Health at CDC and Emory University.

As an unpaid volunteer, Dr Graven was Chief Architect and Co-designer of the country-wide health information systems (HIS) in both Belize and St. Lucia. As of September 2008, Belize and St Lucia are the only countries in the world with country-wide HIS that serves all sectors, including hospitals, clinics, emergency, ambulance, pharmacies, laboratories, radiology, physician offices, and medical supply chain. The Belize System was recognized as the best of its kind, world-wide, by the Health Metrics Network of the World Health Organization on September 16, 2008. Dr Graven has been appointed, and Gazetted, Senior Advisor for Health Affairs to the Governments of both Belize and St Lucia. The system is currently being deployed in St Vincent and the Grenedines.

Dr. Graven's clinical work has involved care of critically ill babies, currently at the IWK Health Centre in Halifax, which is the referral centre for Canada's Atlantic Provinces (Nova Scotia, New Brunswick, Newfoundland & Labrador, and Prince Edward Island). He has served as consultant for Neonatal-PerinatalMedicineforbabiesfromBermuda,Belize,Ethiopia,Haiti, Mexico, St. Lucia, Tanzania, and in the US. He is a Regional Trainer for the Neonatal Resuscitation Program in the US and Canada.

Dr. Graven is married and has two teenage sons. They live just outside of Halifax in Nova Scotia Canada.



ROGER MAGNUSSON

PROFESSOR OF HEALTH LAW AND GOVERNANCE FACULTY OF LAW UNIVERSITY OF SYDNEY

Roger Magnusson is a Professor of Health Law & Governance in the Faculty of Law, University of Sydney. He serves as Associate Dean (Postgraduate Coursework) and is a member of the Academic Board of the University. His research interests are in public health law and governance, health law and bioethics. He has an extensive record of refereed publications in these areas. He has made many presentations to conferences, submissions to law reform bodies and has served government policy processes in a variety of other capacities.

Roger has Arts/Law degrees from the Australian National University (1988), and a PhD in Law (1994) and a Graduate Diploma in Managing Development (2007) from the University of Melbourne. During the mid 1990s he was a Postdoctoral Research Fellow funded by the Australian government, working on legal and policy issues associated with HIV/AIDS. In 2002 he published Angels of Death: Exploring the Euthanasia Underground (Melbourne University Press; Yale University Press) which reported on the practice of illicit, "underground" physician-assisted suicide and euthanasia among health professionals working in HIV/AIDS health care in Australian cities and in San Francisco. Roger is a member of the TransmissibleSpongiformEncephalopathiesAdvisoryCommittee (TSEAC) of Australia's National Health & Medical Research Council, which advises the Australian Government on the risks posed by Creutzfeldt Jakob Disease and variant CJD (the human equivalent of "mad cow disease").

During 2006-08, Roger was a member of the Advisory Committee to the Australian Law Reform Committee in its recent, comprehensive review of Australia's Privacy Act 1988 (Cth): see http://www.austlii.edu.au/au/other/alrc/publications/reports/ 108/. He has also been an invited participant in roundtable discussions on shared electronic health records, and on health information privacy, chaired by the National e-Health Transition Authority, which was established by the Council of Australian governments to develop the business case for a national network of shared electronic health records. Roger's main research interests are in the role of law and regulation in responding to chronic, non-communicable disease, and its risk factors.



ERIC RASMUSSEN

CHIEF EXECUTIVE OFFICER

Eric Rasmussen arrived as President and Chief Executive Officer of InSTEDD in October 2007. Until selected as CEO of InSTEDD. Dr. Rasmussen was both Chairman of the Department of Medicine within Naval Hospital Bremerton near Seattle, Washington, and an advisor in humanitarian informatics for the US Office of the Secretary of Defense. He holds academic positions at several institutions and has been a Principal Investigator for both the Defense Advanced Research Projects Agency (DARPA) and for the National Science Foundation. He is a Reviewer for the Journal of the American Medical Association (JAMA) and the American Journal of Public Health and sits on several advisory boards, including the Crisis Management Resources Board for the National Academy of Sciences. He has a number of publications and has been awarded several personal, unit, and theater military decorations, including a Presidential Legion of Merit. Beginning around age 17, Dr. Rasmussen spent seven years enlisted in nuclear submarines before leaving the Navy to receive his undergraduate and medical degrees from Stanford University. After graduate work in molecular biology at Los Alamos National Laboratory and teaching in Haiti, he completed a Residency in Internal Medicine and re-entered the Navy as Chief Resident in Medicine at the Navy Medical Center in Oakland, California. Subsequent Navy positions included three years as Fleet Surgeon for the US Navy's Third Fleet.

Entering the field of Disaster Medicine in 1997, Dr. Rasmussen, with an additional European Master's Degree in Disaster Medicine, served on the Afghanistan humanitarian support planning staff within US Central Command Headquarters (CENTCOM) in 2002, and later as a physician to the Iraq Disaster Assistance Response Team (DART) for the Iraq War in 2002-2003. As a member of the DART, he served within the International Humanitarian Operations Center in Kuwait and was later selected for the DARPA 2003 "Sustained Excellence in a Principal Investigator" award.

Further work as Director of the Strong Angel series of international humanitarian response demonstrations led to work in Afghanistan in 2004 and 2007, and in Indonesia as head of a Civil-Military Coordination Team for the tsunami response in Banda Aceh in early 2005. Later in 2005, he deployed with Joint Task Force Katrina in New Orleans, coordinating a small portion of the relief response after Hurricane Katrina.

In addition to his responsibilities at InSTEDD, he currently serves as Permanent Advisor to the United Nations Secretary-General's High-Level Forum on Water Disasters, as a member of the US Congressional Task Force on Global Biosurveillance, and as a member of Kofi Annan's Global Humanitarian Forum in Geneva. Eric has been married for more than 25 years to Demi, and has daughters Melissa and Faith. He divides his time between Palo Alto and his home on Bainbridge Island near Seattle.

SALLY STANSFIELD



EXECUTIVE SECRETARY HEALTH METRICS NETWORK

Sally Stansfield is the Executive Director of the Health Metrics Network (HMN), a global partnership founded to improve the supply and use of information to improve decision making for health in developing countries. For HMN's global network and for its host, the World Health Organization, Dr. Stansfield manages the technical and financial contributions of HMN partners to accelerate reform of health information systems for improved health outcomes.

Prior to 2006, Dr. Stansfield was the Associate Director for Global Health Strategies of the Bill & Melinda Gates Foundation. She draws upon more than 30 years of clinical and public health practice, experience in research agencies, universities, governments, non-governmental organizations, and multilateral agencies. Dr. Stansfield's areas of expertise include public health research, policy, strategic planning, program design and development, evaluation, and the development of health information systems. She has designed and managed programs for the US Centers for Disease Control, the US Agency for International Development and Canada's International Development Research Centre and has advised governments in Bangladesh, Cambodia, DR Congo, Ethiopia, Malawi, many other countries, primarily in Asia and Africa.

Her many awards include the Alpha Omega Alpha medical honorary, the International College of Surgeons Award for Scholarship, the Public Health Service Distinguished Service Commendation, a Fulbright Fellowship, and the Yale Tercentennial Medal.

Prince Mahidol Award Conference 2010

PARALELL SESSION 1.2:

TRACKING AND COMMUNICATING PUBLIC HEALTH EMERGENCIES FROM THE FRONT LINES



DIGITAL DISEASE DETECTION — HARNESSING THE WEB FOR PUBLIC HEALTH SURVEILLANCE

JOHN S. BROWNSTEIN, PH.D., CLARK C. FREIFELD, B.S., AND LAWRENCE C. MADOFF, M.D.

The Internet has become a critical medium for clinicians, public health practitioners, and laypeople seeking health information. Data about diseases and outbreaks are disseminated not only through online announcements by government agencies but also through informal channels, ranging from press reports to blogs to chat rooms to analyses of Web searches. Collectively, these sources provide a view of global health that is fundamentally different from that yielded by the disease reporting of the traditional public health infrastructure.¹

Over the past 15 years, Internet technology has become integral to public health surveillance. Systems using informal electronic information have been credited with reducing the time to recognition of an outbreak, preventing governments from suppressing outbreak information, and facilitating public health responses to outbreaks and emerging diseases. Because Web-based sources frequently contain data not captured through traditional government communication channels, they are useful to public health agencies, including the Global Outbreak Alert and Response Network of the World Health Organization (WHO), which relies on such sources for daily surveillance activities.

Early efforts in this area were made by the International Society for Infectious Diseases' Program for Monitoring Emerging Diseases, or ProMED-mail, which was founded in 1994 and has grown into a large, publicly available reporting system, with more than 45,000 subscribers in 188 countries.2 ProMED uses the Internet to disseminate information on outbreaks by e-mailing and posting case reports, including many gleaned from readers, along with expert commentary. In 1997, the Public Health Agency of Canada, in collaboration with the WHO, created the Global Public Health Intelligence Network (GPHIN), whose software retrieves relevant articles from news aggregators every 15 minutes, using extensive search queries. ProMED and GPHIN played critical roles in informing public health officials of the outbreak of SARS, or severe acute respiratory syndrome, in Guangdong, China, as early as November 2002, by identifying informal reports on the Web through news media and chat-room discussions.

More recently, the advent of openly available news aggregators and visualization tools has spawned a new generation of disease-surveillance "mashups" (Web application hybrids) that can mine, categorize, filter, and visualize online intelligence about epidemics in real time. For instance, HealthMap is an openly available public health intelligence system that uses data from disparate sources to produce a global view of ongoing infectious disease threats. It has between 1000 and 150,000 users per day, including public health officials, clinicians, and international travelers. Other similar systems include MediSys, Argus, EpiSPIDER, BioCaster, and the Wildlife Disease Information Node. Automated analysis of online video materials and radio broadcasts will soon provide additional sources for early detection.

The ease of use of blogs, mailing lists, RSS (Really Simple Syndication) feeds, and freely available mapping technology has meant that even an individual expert can create an important global resource. For instance, Declan Butler, a reporter at Nature, took aggregated data from various sources to provide a view of the spread of H5N1 avian influenza on a Google Earth interface. Similarly, Claudinne Roe of the Office of the Director of National Intelligence produces the Avian Influenza Daily Digest and blog, a collection of unclassified information about confirmed and suspected human and animal cases of H5N1 influenza.

Although news media represent an important adjunct to the public health infrastructure, the public health officials, clinicians, and international travelers. Other similar systems include MediSys, Argus, EpiSPIDER, BioCaster, and the Wildlife Disease Information Node. Automated analysis of online video materials and radio broadcasts will soon provide additional sources for early detection. The ease of use of blogs, mailing lists, RSS (Really Simple Syndication) feeds, and freely available mapping technology has meant that even an individual expert can create an important global resource. For instance, Declan Butler, a reporter at Nature, took aggregated data from various sources to provide a view of the spread of H5N1 avian influenza on a Google Earth interface. Similarly, Claudinne Roe of the Office of the Director of National Intelligence produces the Avian Influenza Daily Digest and blog, a collection of unclassified information about confirmed and suspected human and animal cases of H5N1 influenza. Although news media represent an important adjunct to the public health infrastructure, the officials, clinicians, and ordinary citizens,

such tools could help to guide medical decision-making and underscore the importance of vaccination and other preventive measures.

An example of the power of search-term surveillance can be found in an examination of the recent peanut butter-associated outbreak of Salmonella enterica serotype Typhimurium. Using Google Insights for Search, a search-volume reporting tool from Google, we compared the epidemic curve of onset dates for confirmed infections with trends in the volume of Internet searches on related terms in the United States. Search terms included "diarrhea," "peanut butter," "food poisoning," "recall," and "salmonella," and search volumes were compared with the corresponding volumes from the previous year. The initial public report of salmonella was released on January 7, 2009, triggering an increase in searches for "salmonella," "recall," and "peanut butter," but we saw earlier peaks in searches for "diarrhea" and "food poisoning." Admittedly, these data provide only preliminary evidence of an emerging problem and require further study, but they highlight possibilities for early disease detection.

Though mining the Web is a valuable new direction, these sources cannot replace the efforts of public health practitioners and clinicians. The Internet is also providing new opportunities for connecting experts who identify and report outbreaks. Information technologies such as wikis, social networks, and Web-based portals can facilitate communication and collaboration to accelerate the dissemination of reports of infectious diseases and aid in mobilizing a response. Some scientific societies are now leveraging technologies for distributed data exchange, analysis, and visualization. For instance, the International Society for Disease Surveillance has created the Distributed Surveillance Taskforce for Real-Time Influenza Burden Tracking and Evaluation (DiSTRIBuTE), a group of state and local health departments that use the Web to share, integrate, and analyze health data across large regions. And the International Society of Travel Medicine, in collaboration with the Centers for Disease Control and Prevention (CDC), has created the GeoSentinel project, which brings together travel and tropical-medicine clinics in an electronic network for surveillance of travel related illnesses. Similarly, the Emerging Infections Network, administered by the Infectious Diseases Society of America in collaboration with the CDC, is a Web-based network of more than 1000 infectious disease specialists that is geared toward finding cases during outbreaks and detecting new or unusual clinical events.

Broader Web-based networks are also proving useful for surveillance. Social-networking sites for clinicians, patients, and the general public hold potential for harnessing the collective wisdom of the masses for disease detection. Given the continued deployment of personally controlled electronic health records, we expect that patients' contributions to disease surveillance will increase. Eventually, mobile-phone technology, enabled by global positioning systems and coupled with short message service messaging (texting) and "microblogging" (with Twitter), might also come into play. For instance, an organization called Innovative Support to Emergencies, Diseases, and Disasters (InSTEDD) has developed open-source technology to permit seamless cross-border communication between mobile devices for early warning and response in resource-constrained settings.

These Internet-based systems are quickly becoming dominant sources of information on emerging diseases, though their effects on public health measures remain uncertain. Information overload, false reports, lack of specificity of signals, and sensitivity to external forces such as media interest may limit the realization of their potential for public health practice and clinical decision making. Sources such as analyses of search-term use and news media may also face difficulties with verification and follow-up. Though they hold promise, these new technologies require careful evaluation. Ultimately, the Internet provides a powerful communications channel, but it is health care professionals and the public who will best determine how to use this channel for surveillance, prevention, and control of emerging diseases.

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CASE STUDY: GOOGLE GADGET FOR INFLUENZA SURVEILLANCE

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BACKGROUND

On August 8, 2009, Typhoon Morakot brought massive flooding, mudslides, and destruction throughout the Southern part of Taiwan and was deemed the deadliest typhoon to hit the island in 50 years. Official reaction was slow, disorganized, and unable to manage the crisis at its critical beginning stages, revealing a fundamental weakness in the government's first-line command system. In contrast, unofficial efforts organized by volunteers used rapid, web-based methods such as the BBS, bulletin board system, to plot flooded areas and destroyed bridges on Google maps, promote collaboration among volunteers from various parts of the island, compile resources, and provide comprehensive lists of locations for affected communities to receive emergency aid. These successful interventions provided inspiration for a citizen-powered, webbased surveillance system for emerging infectious diseases such as the 2009 influenza pandemic.

AIMS OF THE PROJECT

This project implements an informal surveillance system utilizing bi-directional communication between researchers, public health workers, and the public. Web users are targeted as citizen sentinels for reporting flu activity in their surrounding environment (i.e. schools, dorms, workplaces, public transportation, hospitals and local communities). This method encourages direct and timely monitoring of epidemics from within communities and provides an innovative means for promoting community health awareness. The tool endeavors to inform both the public and health officials of the most current flu conditions within local neighborhoods by providing immediate feedback of community-reported flu activity on a scalable Google map, as well as updated temporal epicurves and graphically rendered breakdowns of high-risk age groups/ locations in real time. In addition, visitors to the web site or subscribers to the gadget on iGoogle, are able to view automatically updated RSS (Really Simple Syndication)-

generated flu news, latest health education programming, and National Taiwan University and Taiwan CDC-produced videos.

IMPLEMENTATION

Providing an interface that is free, accessible to the public, and easily maintained were top priorities in our design. We chose to utilize Google gadgets and a Google web page for these reasons. Site managers and research staff are able to review reports and maintain the web site through an internal database and symbology setting created through Google excel. In addition, our research team is able to update and add new applications to our gadget quickly and seamlessly using a variety of open access Google tools.

To encourage participation in our survey tool and prevent reporting fatigue, we limited our report form to eight short questions that could be addressed by selecting answer choices from a drop-down menu. Users who experience or witness flu-like symptoms in others are asked to estimate the onset date for symptoms, describe symptoms, their relationship to the symptomatic person/location, their occupation, possible infected sites, the potential susceptible population (divided into four age groups: 0-12, 13-24, 25-64, 65+), estimated infected numbers within the members of the age-group, and the approximate address of the reported incident. After reports were submitted, a risk map, case number epicurve, bar chart of symptom counts, chart describing age distribution, and map of possible infected sites were automatically updated and publicly displayed for seven days.

Project staff manually compiled additional flu-related news, recent reports from experts, official CDC policy announcements (i.e. vaccination policies), Youtube videos with health education programming, and editorials from local magazines to provide comprehensive health education. When H1N1 vaccines became available to the general public, we followed the example of Google's flu shot finder program in the United States and geocoded all H1N1 vaccination locations in Taipei so that residents could locate vaccination centers closest to their homes on a Google map. The tool also provided timely news on the progress of the epidemic by automatically refreshing the web site to display news reports from the last 48 hours through the Google News service. In addition, links to national and international resources including the MMWR in United States, Taiwan-CDC's official H1N1 website, Japanese surveillance information, European surveillance information, HealthMap,

ProMed, and Google flu trends were placed in the web site's sidebar to provide insight on the epidemic's global scale.

DISCUSSION AND CONCLUSION

Anonymous reports submitted to our program may result in duplicate entries. We have utilized the attack rate formula to counteract this effect but cannot fully negate the possibility of double counts.

The major challenge of this project has been in the large-scale promotion of the gadget and in encouraging participation in case reporting. We launched a multi-platform strategy to publicize our tool: promoting the new project on newspapers, posters, web bulletin boards, and email listservs. Although many installed the gadget and have accessed the website, reporting rates remain low. We have therefore begun to proactively build a network of citizen sentinels among web-savvy students nationwide and improve reporting interface (i.e. installing more prompts in the health education and news components of the web site for quick link-over to the reporting tool). In addition, an international version of our gadget that will extend our surveillance to multiple infectious diseases and provide health education in various languages is currently in development. In the spirit of collaboration and transparency, we intend to share our platform and tools freely with other researchers and countries.

SURVEILLANCE AND RESPONSE TOOLS

CHANNE SUY

PRODUCT MANAGER, INSTEDD (ILAB) CAMBODIA

InSTEDD's Innovation Lab (iLab) in Phnom Penh is working closely with partners in the Cambodian government such as the Ministries of Health and Agriculture providing technology support to strengthen their work and increase their capacity for effective disease surveillance and response. The result of this collaboration has been the development of technologies for surveillance and response built in Cambodia.

InSTEDD has worked with the Cambodian CDC in the Ministry of Health in an agile process where needs are observed and understood and technology is developed in country that could help these agencies work more effectively and efficiently. For example, Rapid Response Teams rely on making phone calls to each other during outbreaks – which is expensive and leaves no history of important data. InSTEDD worked with them to improve aspects of the communication they wanted help on and introduced an SMS Group Communication tool called GeoChat. GeoChat provides real time group SMS that could work on the web or on the phone. The cost is much lower than voice call and it is broadcasted to everyone in the team, at the same time the message history is saved for a future analysis.

InSTEDD also worked with NaVRI (National Veterinary Research Institute) of the Ministry of Agriculture to improve their Avian Influenza hotline system. This used to be a paper-based system that made analysis and historical tracking hard. The InSTEDD iLab proposed to them the combination of mobile and computer systems that give hotline agents GUI forms on their Phones for easier data collection, a backend system to visualize and report the data, and a field investigation system for getting more information about suspect cases. These solutions enablefaster and more accurate data collection, and were designed and built locally so future changes and adaptations are possible. In addition, InSTEDD's iLab has produced an SMS-based appointment reminder system that helps Community Health Workers engage HIV patients to improve continuity of care. While not strictly a rapid outbreak surveillance and response activity, getting indicators from such systems can help improve quality improvement efforts and link to prevention efforts in the future; and is another example of a distributed system for health built by local staff.

SMS FOR DISEASE SURVEILLANCE, MUKDAHAN - SAVANNAKHET CASE STUDY

DR. PRAPAS WEERAPOL

EXPERT OF PREVENTIVE MEDICINE AND MUKDAHAN MBDS ASSOCIATE PROVINCE COORDINATOR, MUKDAHAN HEALTH OFFICE, THAILAND

The Public Health Office in Mukdahan province, the ICT for Development of the Thai Health Promotion Foundation and InSTEDD organization has initiated the use of SMS for disease surveillance system in Mukdahan – Savannakhet, Lao PDR. The idea of bringing in new technology sprung from the initiation of Mekong Basin Disease Surveillance project (MBDS) which has been established since 2004. The project team members believe that the implementation of SMS for disease surveillance system will enhance the effectiveness in epidemiology report. In order to weave a new network of surveillance staffs in local and national and international level, InSTEDD's expertise in program development has been brought in and the program called GeoChat has been introduced. GeoChat is an open-source program specially developed by InSTEDD for the use of group communication. The program is integrated with an online map which allows surveillance staffs in the network to effectively communicate and allows everyone in the network to know exactly where the report is sent, who submitted the report and what action has been done. The program offers varieties of communication channels including SMS, email and online mapping. GeoChat system is capable analyzing and processing data in the format that can be viewed on website. Workshop sessions have been organized to build network of people from Thailand and Lao PDR. Health staffs who attended the workshop had been equipped with necessary skills including registration to the network, the use of the program and how to send the report through SMS. Timeline of pilot phase has been set up and the code of conduct has been informed to standardize the SMS report. There are 3 categories of report includes the ILI case found in the hospitals and in communities, other cases of disease under surveillance and news and notifications. GeoChat program has tested and implemented since March 2009 until present.

Disease surveillance network in Mukdahan, Thailand consists of 116 members. They are divided into 8 teams. The network in Savannakhet, Lao PDR consists of 21 members. These members are acting as local representatives. A team of staffs to cooperate in the international level will be on duty in the near future.

Analysis of the daily report shows that total number of text message sent to the system between September 29, 2009 and November 30, 2009 was 260 while 22 text messages of the total messages sent were from local network members and the rest were from provincial network members. 36.4% of total text messages sent were news and notifications. Number of ILI reports were accounted for 33.01% and number of other disease under surveillance reports were accounted for 30.59% of total number. 64 messages (31.06%) of the total number were from provincial network members, 39 messages (18.93%) of total number were from network members of Nikomkamsoi district and 36 messages (17.74%) of total number were from those of Kamcha-i district.

Feedback from network members shows that they all see the necessity and value of the system. They found that they could spread out health report to everyone in such speedy yet effective method. Diseases under surveillance that have been found and reported include H1N1 and dengue fever. This cost-effective real-time report system informs the location of where the disease is found. The program and the structure are user-friendly. And the analysis gives a collective data to Public Health Department officials and allows them to have a better decision making for disease control.

Members from the pilot group agreed that the SMS disease surveillance system should also be implemented in other remote areas. Volunteers from local communities, Local Live Stock Department officials and/or people with high potential to be infected are to be involved. The Thai Health Promotion Foundation and InSTEDD are working together in developing a better system to be implemented in other local communities as well as in the international level.



DAVID AYLWARD

EXECUTIVE DIRECTOR MHEALTH ALLIANCE

DAVID AYLWARD is the first Executive Director of the mHealth Alliance (mHA). mHA was founded by the United Nations Foundation, Rockefeller Foundation and Vodafone Foundation will generate public and private collaboration in support of mHealth innovation and projects that address global health needs with the mission of extending quality health care using modern information and communications technology to the full extent of wireless networks in developing countries. He is an expert on the intersection of public policy and private initiatives in the development of US domestic and international communications and information technology, emergency and healthcare communications and information systems, and related fields.

He began his career in these areas as Legislative Director to Rep. Timothy Wirth (D-Colo), a key member of the House of Representatives. After serving as Chief Counsel and Staff Director of the House Telecommunications and Finance Subcommittee for Wirth during the advent of competition in telecommunications, the breakup of AT&T, and the emergence of the cable television industry, as well as the beginning of electronic trading in stocks, he established National Strategies, a successful business and public policy consulting firm for 24 years.

He was a founder in 1998 and then Chief Strategist and Director of the 100 organization COMCARE Emergency Response Alliance, the mission of which was improving America's emergency response system, including medical response. David's particular focus was on bringing the business process and technical strengths of modern commercial communications and information technologies into the emergency response and medical response realms. In addition, he has represented a wide range of communications, healthcare, finance, public service media, children's television and other clients, including starting and managing the first satellite competitor to Intelsat over the Pacific Ocean and a land mobile radio company.

David has a BA in Government from Dartmouth College, where he was Editor in Chief of the daily newspaper, and a JD with High Honors from George Washington University Law School.



JOHN S. BROWNSTEIN

HEALTHMAP CO-CREATOR, ASSISTANT PROFESSOR CHILDREN'S HOSPITAL BOSTON, HARVARD MEDICAL SCHOOLHARVARD-MIT DIVISION OF HEALTH SCIENCES AND TECHNOLOGY

Dr. John S. Brownstein is an Assistant Professor of Pediatrics at Harvard Medical School and Director of the Computational Epidemiology Group at the Children's Hospital Boston Informatics Program of the Harvard-MIT Division of Health Sciences. Dr. Brownstein was trained as an epidemiologist in the Department of Epidemiology and Public Health at Yale University. His research is dedicated to statistical and informatics approaches aimed at improving public health surveillance and practice. This research has focused on a variety of infectious disease systems including malaria, HIV, dengue, West Nile virus, Lyme disease, RSV, salmonella, and influenza.. He is also leading the development several novel disease surveillance systems, including HealthMap.org, an internet-based global infectious disease intelligence system. The system is currently in use by the CDC, WHO, DHS, DOD, HHS, amd EU among others. Dr. Brownstein has advised the World Health Organization, Institute of Medicine, the US Departments of Health and Human Services and Homeland Security, and the White House on real-time public health surveillance. He has used this experience in his role as Vice President of the International Society for Disease Surveillance. He has authored over fifty articles in the area of public health surveillance. This work has been reported on widely including pieces in the New England Journal of Medicine, Science, Nature, New York Times, The Wall Street Journal, CNN, National Public Radio and the BBC.


TA-CHIEN CHAN

NATIONAL TAIWAN UNIVERSITY

Mr. Chan has had research experiences mainly in health informatics and health geographic information system (GIS). He graduated with a master degree (M.S.) from the Institute of biomedical informatics, National Yang-Ming University in 2006. At the same year, he won the best master thesis award of Taiwan Geographic Information Society. Ta-Chien is currently a doctor candidate at the Institute of Epidemiology, College of Public Health, National Taiwan University. He is also working part-time at the National Health Research Institute (NHRI) and Centers for Disease Control in Taiwan for data analysis in health informatics, GIS applications to public health, surveillance of infectious diseases and environmental health The main study focuses of his recent research works were on understanding the influenza epidemiology and improving the surveillance methods/systems in Taiwan.

MARK S. SMOLINSKI

DIRECTOR, GLOBAL HEALTH GOOGLE.ORG

Mark S. Smolinski, M.D., M.P.H. joined Google.org in 2006 as a specialist in global public health disease surveillance and response and is currently Director of their Global Health program. Prior to Google, Mark served as Vice President for Biological Programs at the Nuclear Threat Initiative, a public charity directed by CNN founder Ted Turner and former U.S. Senator Sam Nunn. While at NTI, Mark led the development of a regional disease surveillance system linking Israel, Jordan, and the Palestinian Authority, demonstrating the power of health as a diplomatic tool even in areas of longstanding conflict. Similarly, he joined forces with the Rockefeller Foundation to improve regional capacity to respond to avian and human influenza among Thailand, Vietnam, Cambodia, Lao PDR, Myanmar, and China. He has also worked with public health partners in Russia, the former Soviet Union, India, Pakistan, and Bangladesh. Prior to NTI, Mark was the study director for a landmark report from the Institute of Medicine of the National Academy of Sciences, the Emergence, Detection, and Response to Microbial Threats to Health. Mark has also served as an advisor to the World Health Organization, Senior Advisor to the U.S. Surgeon General and Assistant Secretary of Health, and an Epidemic Intelligence Officer at the U.S. Centers for Disease Control and Prevention. Mark was a member of the investigation team that discovered hantavirus in 1993 in Southwestern United States. Mark is a trained Internist and board certified in Preventive Medicine and Public Health. A native of Michigan, Mark received his B.S. and M.D. from the University of Michigan in Ann Arbor. He received his Masters in Public Health from the University of Arizona.



CHANNE SUY

PRODUCT MANAGER INSTEDD (ILAB) CAMBODIA

Channe joined InSTEDD Innovation Lab as a Product Manager in August 2008. Her primary focus is to capture user requirements on all aspects that affect the quality of products. Beside that she also does software usability design and testing as well as provides on-going support to the clients.

Channe has over five years of working experiences in software development, system design, coding, testing, facilitate training and customer support in Information Technology Company and NGO. Over the years she has been working on open source web-based applications and then started the mobile application when she joined InSTEDD.

Beside, Channe is a volunteer in an IT community of Cambodia which is meant to help enhance the quality of students and organize events for IT people to share and learn new things from each others.

Channe graduated her Master in Computer Application from Bangalore University, India in 2006.



IENG VANRA

IT CONSULTANT WORLD HEALTH ORGANIZATION/CDCMOH CAMBODIA

IENG Vanra, IT Specialist for surveillance support to Ministry of Health of the Royal Government of Cambodia. His main responsibility is to develop a surveillance application and managing the IT system at CDC Department.

He has spent almost three years on developing a database to collect the information about the HIV/AIDS tested patients as well as providing related training to facilitate the physicians or doctors to better analyze and produce the monitoring report.

He has joined WHO Cambodia CSR team in early 2006 and he has been invited to WHO Headquarter for training on how to create the surveillance application. At the same time the CamEWARN system (Cambodia Early Warning and Response Network) has been developed and collected the 12 communicable diseases under surveillance in Cambodia. By combining with CamEWARN, in 2008, he created another new system called CamEWARNSMS to facilitate the health workers for sending the data on time via a normal SMS (short message service).

He is also responsible for maintenance the website of Communicable Disease Control department as well as uploading all the information regarding to communicable diseases.

Mr. leng earned his Bachelor degree from Royal University of Phnom Penh and currently is pursuing his Master of Science in Information Technology Engineering (MITE). His area of interest /research interests is/are health information system.



PRAPAS WEERAPOL

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Dr. Prapas Weerapol received a Master's Degree of Public Health in Hospital Administration from the Faculty of Public Health, Mahidol University in 1995. He also received a Diploma Board of Preventive Medicine (Clinic) in 1990 and a Diploma of Family Medicine in 2004 from the Thailand Medical Council.

He is an experienced general practitioner. He worked for a rural hospital for 11 years and spent 8 years in the field of preventive medicine and as the Director of a community rural hospital in Chantaburi Province in the eastern region of Thailand.

From 2004 until present, he has been working for the Mukdahan Public Health Office in the position of MBDS Associate Province Coordinator and Expert of Preventive Medicine collaborating with the border health team for the surveillance and disease control. Maintaining the coordination and communication between Thailand and Laos (Savannakhet) and finding solutions to real-time communication in SRRT are also included in his responsibilities.

With assistance from the Rockefeller Foundation, the ICT for Health Promotion Program under the Thai Health Promotion Foundation (ThaiHealth) and InSTEDD, the use of SMS for disease surveillance system was piloted in Thailand's Mukdahan and Laos' Suvannakhet. Initially, the new technology was developed by the Mekong Basin Disease Surveillance project (MBDS) in 2004. We believe that the implementation of the system would strengthen the effectiveness in epidemiology report. In addition, to weave members of the surveillance network at all levels, InSTEDD's GeoChat has been introduced.

PARALELL SESSION 1.3:

INFORMING THE RESPONSE TO CHRONIC DISEASES



INFORMING THE RESPONSE TO CHRONIC DISEASES: THAI NATIONAL HEALTH EXAMINATION SURVEY

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INTRODUCTION

Information on magnitude and distribution of chronic diseases and related risk factors in population is important to countries in making strategic plan for prevention and control. The information can be used to target health priority issue of the population and high risk group, as well as in taking appropriate action to prevent the potential chronic diseases burden in the future. The use of chronic disease data at the health service, provincial health administration and country level helps better decision making on priority setting of intervention, resource allocation and management programs. The data when periodically collected are critical for monitoring and evaluation of the control programs.

Many developed and developing countries in the world use health survey data to assess prevalence of common chronic disease and risk factors profiles. Surveillance on key health behaviors, diabetes, obesity, hypertension and lipids are collected in the surveys. World Health Organization (1) advocates low and middle income countries about three steps to collect common risk behavior eg. the first step includes the collection of data on diet, tobacco use and alcohol consumption. The second step adds physical measurement of height and body weight. The third step incorporates collection of blood sample for measurement of lipids and glucose. Countries could apply these steps in accordance with their availability of resources. Countries with more resources usually add more sophisticated measurements and biomarkers of exposure and diseases, for example measurement of cotinine to validate smoking exposure. The survey data collected are then analyzed, synthesized and disseminated to public, health care professional and policy level.

THAI NATIONAL HEALTH EXAMINATION SURVEY

The National Health Examination Survey (NHES) in Thailand is a series of periodic surveys about the health of people in Thailand. The survey was first started in 1992 followed by periodic surveys in 1997, 2004 and 2009. For the first two surveys, they were conducted by the Thai Health Research Foundation and National Health Foundation with financial support from the Bureau of Planning and strategy, Ministry of Public Health. The latest two surveys were conducted by the National Health Survey Office, Health System Research Institute with co-funding from the Ministry of Public Health, Thai Health Promotion foundation and National Health Security office. The aims of the survey are to: determine the prevalence of certain health conditions and risk factors, provide trends data on health, and examine the distribution of health conditions and risk factors by age, sex, geographic region and socioeconomic status. The main challenge of the survey is how to secure budget for development of prospective plan and sustain the survey system.

SURVEY CONTENT AND TOOLS

The Thai fourth NHES included non-institutionalized Thai population aged 1 yr and over including a sample of 30,000 individuals in 21 provinces. Multi-stage random sampling was applied. The survey consists of questionnaire interview and measurement including anthropometric, and blood pressure measurement and analyses of blood samples for lipid profile and glucose. Questions included socio-demographic variables, health state condition. Since cardiovascular disease (CVD) risk factors and associated risk factors were leading burden of disease, obesity, hypertension, diabetes, smoking, vegetable and fruit consumption, and physical activity were included in the survey. Dietary-recall assessment was also included in the fourth survey. The components allow the analysis of interrelation between many risk factors and health conditions.

FIELD WORK

The field survey consists of 2 steps ; first trained field staff make a household visit to the selected subjects seeking permission from each selected adults and parents' and children to consent the interview and blood sample. Appointment for the interview and physical measurement were made. On interview date, participants were interviewed by trained interviewers at a meeting place in the community. Children aged 1-10 years were interviewed in the presence of a parent or guardian. After the interview, measurement of participants' height, weight, and waist circumference were performed. Blood pressure was measured using ambulatory blood pressure measurement and blood samples were drawn from venepunture. Biochemical measurements include total cholesterol, HDL-C, triglyceride, creatinine and fasting plasma glucose. Supporting factors for the survey include technical and operational issues such as standard questionnaire, operational resources, budget, and quality control.

RESULTS

The prevalence of obesity and diabetes steadily increased in 1997, and 2004.(2,3,4) For obesity prevalence, it continues to rise in the 2009 survey, as one-third of the populations aged≥15 yrs. have BMI ≥25 kg/m2. While the trends of smoking decreased in men, the prevalence in women is relatively stable. The prevalence of hypertension is relatively constant over the last two surveys (21%), while the prevalence of high cholesterol increased during 1991 to 1997 and leveled off during 1997 to 2004 and increase again in 2009 (20% having TC \geq 240mg/dL). Prevalence of individuals aged \geq 15 yrs. with \geq 3 multiple risk factors (obesity, high blood pressure, smoking, diabetes, high total cholesterol) steadily increases to 8.4% in 2009. All the prevalence of risk factors are higher in urban than in rural; however, the gap between them become closer in the later surveys. The findings also witness some difference in distribution of risk factors across regions as well as evidence of health inequality.

CONCLUSION

The NHES data contribute to the understanding of health status and risk factors of Thai population across geographic regions and urban/rural by gender and age groups. It is crucial to ensure that the policy level, health professionals and public are informed by this information. The survey data have identified the critical rising of obesity and diabetes as a public health priority in Thai population. In the past few years, a national strategic plantoreduce chronic disease related to CVD has been set. Programmes on prevention and control of obesity and diabetes had been launched. In response to the finding of high percentage of unawareness of diabetes and hypertension cases, screening programs of hypertension and diabetes in high risk groups have been campaigned at the local and national levels. Issue on the suboptimal control of blood pressure and blood glucose among cases stipulated quality improvement programs and the revision of management guideline to improve the quality of care. Note that, aside from health information, other strategic interventions are also needed in concert to tackle chronic diseases. The actions include planning, prioritization, development of strategy and programs on NCD control, intersectoral collaboration and community involvement to address the health determinants as well as monitoring and evaluation.(3) Other components of health system to support such mission require commitment of the policy level, financial support and capacity building.

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OPPORTUNITIES TO UNDERSTAND BIO-SOCIO-ENVIRONMENTAL RISKS TO ILLNESS ACROSS THE LIFE COURSE: PROMISES AND PERILS OF BIOBANKS

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Several risk factors have been discovered that influence disease occurrence and progression. Global Disease Burden Study (2004) showed that among 15 to 59 years of age 60% to 90% percent of the diseases are due to tobacco, illicit drugs, ergonomic stressors, and unsafe sex¹. It also observed that most of the risks of death among younger adults are due to injuries, neuro-psychiatric diseases, maternal conditions, and HIV/AIDS. Projections indicate that by 2020, common chronic diseases will account for almost three-guarters of deaths worldwide. These diseases such as cardiovascular diseases, stroke, cancer, diabetes, tuberculosis, and HIV/AIDS have long and complex disease progression. Over the life course, a multitude of biological, social, and environmental factors that may cause these diseases are yet to be discovered. Not only genes but social and environmental factors in which people live and work also influence the risk factors of chronic diseases. Understanding the role of risk factors and their influence over the life course is important for policy formulation and implementation of disease prevention and control programs.

Epidemiological studies on the role of risk factors that have moderate effects, such as relative risk of 1.2, need to collect biological, medical and life style data from a large number of people and follow their health for longer term in the life course to know who develops and who does not develop the disease. Reliable assessment of genetic variants in different populations including documenting any interactions between genes and other risk actors requires studies with thousands, or even tens of thousands of cases and controls^{2, 3}.

Studies across the world have documented the associations for a range of chronic diseases like diabetes type 1 and 2, coronary artery disease, breast cancer, colorectal cancer, prostate cancer, age-related macular degeneration and Crohn's disease⁴. Study of rare diseases motivated the concept of Biobanks⁵. Population based bio-banking is a concept of genetic anthropology. Biobanks are the collection and storage of biological samples such as tissues, blood and cells which can be of prospective or retrospective in nature. Prospective biobank assess the samples from the participants at the start of the study and then follow their health over subsequent years. Retrospective biobank assess the sample from diseased individuals or family-based genetic studies, with aim to track down genes associated with diseases or other traits.

Several factors are motivating the development of population based biological specimen collections. The number of available polymorphic markers (SNPs) is increasing rapidly. Automated molecular techniques and bioinformatics tools are also available for testing of large samples. Biobanks that are linked with medical data promise to accelerate the discovery of vaccines, drugs and diagnostics, and offer multiple long term scientific interests. The Human Genome Project, annotation of single-nucleotide polymorphisms (SNPs) within the genome, developing ultrahigh-throughput genotyping, small molecule detection methods, and powerful software to analyze the mass of data that is generated, now make possible the discovery of the allelic and biological variant that underlie the complex diseases 2. The biobank data is useful to medical geneticists, epidemiologists, academicians, pharmaceutical companies and the biotechnological industry.

Efforts are on to establish biobanks that constitute large population collections across the countries. Population biobanks have been established like the Iceland Health Sector Database; Estonian Genome Project; UK biobank; Kadoorie Study of Chronic Diseases in China, CARTaGENE project in Quebec, Canada; Banco Nacional de ADN in Spain; the International HapMap Project; and several US biobanks, such as the National Children's Study, the Marshfield Clinics' Personalized Medicine Research Project and the National Health and Nutrition Examinations Survey, Indian National Biobanks6.

Apart from improving the understanding of the risk factors and disease patterns in the life course, biobanks also opened several issues of concern such as the need for individual/ family consent for storage of samples. Many European guidelines take the view that general consent is acceptable for using the samples in future, whereas, US and Canadian policy follows a more rigorous standard consent⁶. Issue of national resource exploitation is another area of concern which is being discussed among scientific, regulatory and administrative authorities⁷. Several countries (e.g., Iceland, Sweden, France and Estonia) have issued specific legislations regarding biobanking⁸. Apart from this several International and National Bioethics Committees are considering another area of concern which includes identifiers handling, physical security, sample and information transfer. The breach in confidentiality can cause individual/family discrimination and stigmatization⁹.

Economic sustainability is another area of concern for establishment of biobanks. Cost ranges from 0.6 million (The Gambian National DNA Bank) to 120 million U.S. Dollars (U.K. Biobank) as a start up cost per person². Typical biobanks are expensive because the serum samples that they collected must be kept cold continuously. Collection of blood samples also requires technical expertise, which is an area of concern in resource limited developing countries. Dried Blood Spot (DBS), in contrast, do not require refrigeration during collection and transport. Even common person him/herself can collect DBS with minimal training. The DBS sample can be easily collected and safely transported by regular mail. The higher acceptability by the participants of DBS versus whole blood collection, lower cost, and ease of handling also enables to achieve much larger sample size with higher participation rates.

More than 75% of the world deaths are due to HIV/AIDS, tuberculosis, malaria in developing countries. Even infectious diseases have cofactors, which make their acquisition or conversion to clinical diseases more likely such as smoking and tuberculosis. Genetic or undiscovered pathogens may help to explain the unprecedented increase in HIV-1 in eastern and southern Africa. Understanding the immune system to fight against infectious diseases can enable new drugs and vaccines. Developing countries also have huge burden of chronic non communicable diseases. Already, four out of five chronic disease deaths occur in developing countries. The genetic and environmental variants that contributes to complex chronic diseases are not necessary the same in geographically segregated populations.

Major roadblock is getting reliable epidemiological evidence about the relevance of variables measured to the development of the disease. Large scale epidemiological fieldwork in developing countries to acquire blood samples systematically linked to relevant measures of disability and future mortality is crucial. Biobanks in western countries use their national health systems, with physicians collecting samples and providing medical data of their patients. In developing countries, however, fewer peoples have access to health care, and linkage to routine health care is not possible. Several developing countries have established their disease and mortality surveillance systems, which could be cost effective platforms to biobanks. A good example is the sample registration system (SRS) of India which enrolls representative population in several hundred small geographic areas covering urban and rural populations by recording their socio-demographic and environmental data and then follows them for a decade for causes of deaths using verbal autopsy¹⁰. Addition of biological specimen collection, especially DBS, can enhance its usefulness. The antenatal clinic HIV surveillance system recommended by the World Health Organization to track the changes in HIV prevalence among pregnant women can also be used to understand the transmission and correlates of HIV infection. Modest enhancement of this system with additional demographic and medical information, as well reliable archiving of samples, would provide a widely practicable resource to investigate the biological correlates o HIV and other diseases.

Genetic studies for association of gene and diseases have shown rapid growth. In 2008, over 7,000 articles on human genome epidemiology were published¹¹. It has been argued that despite having large primary dataset, conclusion of genetic epidemiology studies mostly remains unclear. Evidence based synthesis is required along with the type of evidence achieved, possibility of replication, and evaluation of the bias. Human Genome Epidemiology Network (HuGENet) was formed with global collaboration of individuals and organizations interested in development of the knowledge on gene variation and human health¹². Some consider National and Regional Biobanks are the first step. Others have called for a global consortium to address common ethical issues, data ownership, and data sharing. Joint analysis of important, but uncommon, gene variants will be needed to generate more definitive results than can be generated from the individual studies which would likely be underpowered studies. Expectations from funders and beneficiaries will push toward collaboration, as has happened in Human Genome Project ad Global HIV Vaccine Enterprise. The promise of biobanks should be accessible and affordable studies in diverse populations to permit imaginative search for both rare and common bio-socialenvironmental correlates of global diseases.

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Wichai Aekplakorn is an associate professor in the department of Community Medicine, Faculty of Medicine, Ramathibodi hospital, Mahidol University. His background is a general practitioner. He was trained in the field epidemiology training program and he had worked as a chief of environmental epidemiology section, Division of Epidemiology, Ministry of public health. He has experience in setting up surveillance system for Occupational diseases. Dr. Aekplakorn has his PhD degree in Epidemiology from the School of Public health, University of North Carolina, at Chapel Hill. His early publications were related to an environmental epidemiology related to effects of air pollution exposure and respiratory health. He has worked as research manager for the cardiovascular diseases and risk factors. Recently, his works focus on epidemiology of cardiovascular diseases and risk factors. His research and publications cover the area of obesity, diabetes, hypertension, and metabolic syndrome in both cross-sectional and cohort study design. At present he is a principle investigator of the fourth Thai National Health Examination Survey.



RAJESH KUMAR

PROFESSOR PGIMER SCHOOL OF PUBLIC HEALTH, INDIA

Dr. Rajesh Kumar, Professor and Head of PGIMER School of Public Health at Chandigarh in India, obtained MD in Social and Preventive Medicine in 1984 from Rohtak Medical College and MSc in Epidemiology from London School of Hygiene & Tropical Medicine. His professional life of 25 years is enriched with experience on health system research, planning and management of public health programs, capacity building of public health workforce through teaching in regular degree/diploma courses, and by organizing short term training courses for health professionals and health administrators. He has also worked as Temporary Adviser to World Health Organisation for the development of verbal autopsy tools, epidemiological capacity, NCD surveillance systems, improvement of the NCD capacity strengthening modules, and assistance in organization of workshops/courses in seven South-East Asian countries for the policy makers and program managers on NCDs Prevention and Control.

Dr. Rajesh Kumar has received several awards and honors, notable among these are: British Council Award for Epidemiology Training and Sri Ram Memorial Award for Community Health Research, FellowshipofNationalAcademyofMedicalSciences,IndianPublicHealth Association, and Indian Association of Preventive & Social Medicine, Dr. S. C. Seal, Dr. B. C. Dasgupta, and Dr. Harcharan Singh Oration, and Dr. M. K. Sheshadari Gold Medal for Practice of Community Medicine. He has published 175 research papers in leading scientific journals.

He developed academic programs in Community Medicine and Public Health, coordinated and supervised public health programs in the rural and urban areas. Several collaborative research programs were set up with National Institutes of Health, USA, Johns Hopkins Bloomberg School of Public Health, Baltimore, University of California Berkley, Health Effects Institute, Boston, Center for Global Health Research University of Toronto, and George Institute of International Health, Sydney.

Using community-based surveys conducted in 1990s, he advocated for initiation of healthy heart project in about one million population of Chandigarh which involved surveillance, development of guidelines, training of medical and paramedical personnel, and coordination with several stakeholders. After 3 year implementation, the project evolved into Chandigarh Non Communicable Disease Prevention and Control Program which is one of the first NCD control program funded and implemented by the government. Development and implementation of Rheumatic Heart Disease Control Program in one million population of district Ropar in Punjab state has also been adopted by the government for state-wide implementation. Verbal autopsy tools were developed to measure cause specific mortality which has been implemented by Registrar General of India in the National Sample Registration System. He has coordinated national study for assessment of the impact of targeted interventions on HIV infection in India.



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Rafael Lozano, MSc, MD, is Professor of Global Health at the Institute for Health Metrics and Evaluation (IHME) at the University of Washington and leads the Institute's work on causes of death analysis and the National Health Information System working group. He is also Visiting Research Professor in Medical Sciences "E" Childhood Hospital of Mexico "Federico Gomez."

Prior to joining IHME, Dr. Lozano worked for seven years at the Ministry of Health in Mexico as the General Director of Health Information, where he coordinated the health information system for the Ministry of Health and the production of national health statistics, coordinating information from a number of health sector institutions in Mexico. Overseeing the health information system, Dr. Lozano played a critical role in the construction of Mexico's health reform through a systematic approach to evidence building.

Dr. Lozano has been a leading contributor to epidemiological statistics, theory, and methods, working at the World Health Organization (WHO) in Geneva as Senior Epidemiologist for the Global Program on Evidence for Health Policy for three years, and also at Mexico's National Institute of Public Health, heading up the Department of Epidemiology and the Division of Epidemiological Transition.

Dr. Lozano also spent several years at the Mexican Health Foundation in Mexico, coordinating the Health Needs Assessment unit for the Center for Health and the Economy. He spent two years as a Research Fellow at the Harvard Center for Population and Development Studies.

Dr. Lozano has been instrumental in educating a new generation of epidemiological and health system assessment experts after more than two decades of teaching both undergraduate and graduate courses. Dr. Lozano has also brought his wealth of experience to numerous expert and advisory groups, including the Core Group of the Global Burden of Disease 2005 study, the Technical Advisory Group for the WHO's Health Metrics Network, and PAHO's Health Statistics Advisory Committee. He has also advised numerous countries on health sector strengthening and burden of disease studies, including Chile, Uruguay, Spain, and Colombia. Dr. Lozano has published more than 100 peer-reviewed articles on his research.

He holds an MD from Universidad Nacional Autonoma de Mexico and a Master's in Social Medicine from Universidad Autonoma Metropolitana in Mexico.

PARALELL SESSION 1.4:

GENERATING GLOBAL EVIDENCE:

BIRTHS, DEATHS AND CAUSES OF DEATH



AN OVERVIEW OF THE SAMPLE REGISTRATION SYSTEM IN INDIA.

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Abstract: There are four major sources of vital statistics in India, namely; (a) the Sample Registration System (SRS), (b) the Civil Registration System (CRS), (c) Indirect estimates from the decennial census and (d) Indirect estimates from the National Family Health Surveys (NFHS). The SRS is the most regular source of demographic statistics in India. It is based on a system of dual recording of births and deaths in fairly representative sample units spread all over the country. The SRS provides annual estimates of (a) population composition, (b) fertility, (c) mortality, and (d) medical attention at the time of birth or death which give some idea about access to medical care. The population composition from SRS coupled with the decennial census counts, enables fairly reliable estimate of population in the intercensal periods. Average time to publication of SRS annual reports is about two years. SRS estimates are generally valid and reliable for the country as a whole and for bigger states with more than 10 million population. Recently the sample size of SRS has been increased to allow for estimates by natural divisions within the bigger states. Evaluations during 1970s and 1980s showed that completeness of recording of births and deaths by the SRS, was generally good, and errors in recording of events minimal. However, systematic evaluation of the SRS has not been taken up for quite some time. Indirect estimates for 1990s and after suggests that registration completeness has worsened and interstate variations widened. A pluralistic evaluation framework is recommended.

Key words: Sample Registration Systems; India; SRS; Vital Statistics; Civil Registration Systems

INTRODUCTION:

There are four major sources of vital statistics in India, namely; (a) the Sample Registration System (SRS), (b) the Civil Registration System (CRS), (c) Indirect estimates from the decennial census and (d) Indirect estimates from the National Family Health Surveys (NFHS). The first three are operated by the Registrar General India (RGI) working under the Ministry of Home Affairs. The NFHS is organised by the International Institute of Population Sciences (IIPS), working under the Ministry of Health and Family Welfare. Table-1 gives a bird's eye view of these four sources of vital statistics in India.

Table-1: An overview of sources of vital statistics in India and their usability.

Source	Periodicity	Estimated	Small-Area Parameters	Usability Estimates
SRS	Annual, Since 1970	Fertility and Mortality Indicators.	State Level Estimates for Bigger States.	Representative sample. Regular availability of reports. Relied source of fertility & mortality statistics.
Census	10 Years	Population count by age sex, and area. IMR, Child Mortality	Population counts: Down to village level. Mortality: District Level	Population data, reliable & valid, available within about 2 years. Fertility and indirect mortality estimates: About 8 year time lag.
CRS	Annual, Since 1958	Fertility and Mortality Indicators.	District Level and Large Cities with more than 100000 population.	Less than 50% of deaths are registered. Wide interstate variation. Average time to publication: 45 months until 1994. No report since then.
NFHS	6 Years I- 1992-93 II-1998-99 III- 2005-06	IMR (Indirect Estimates)	State Level Estimates. Sample not enough for district level est.	Indirect estimates. Quick estimates are available within a year of the survey. IMR and fertility indicators, cross tabulated by socioe- conomic variables.

a SRS: Sample Registration System, Operated by the Registrar General, India

b CRS: Civil Registration System, Operated by Local Bodies, Managed by State Governments, Tabulation, Publication and National Coordination by the Registrar General, India

c NFHS: National Family Health Survey, By the International Institute of Population Sciences, Mumbai.

The SRS was conceived during the 1960s, as an interim measure to generate vital statistics until full fledged development of the CRS. The primary objective of the system is to provide reliable annual estimates of vital rates for the states and the country on the basis of a probability sample (RGI, 1971). Pilot studies were taken up in various states from 1964, onwards. By the middle of 1971, the system had established throughout India. The SRS is based on a system of dual recording of births and deaths in fairly representative sample units spread all over the country. Sampling design, registration and validation methodology of the SRS has been published (RGI, 1972; RGI 1993). The sampling frame is revised every ten years and old sample clusters are replaced by new ones. Replacement of existing sample clusters with newly identified clusters usually takes place gradually over a period of 2-3 years. Recently, after the 2001 census, the RGI has replaced old clusters with new ones in one go. The sample size of SRS has also increased over time (Table-2).

S	Year	Sample Units				
Rural	Urban	Total	-	Rural	Urban	Total
2,633,349	1,029,687	3,663,036	1970	2,367	1,256	3,623
	Not Available		1971	2,432	1,290	3,722
			1976	2,450	1,344	3,794
			1979	2,460	1,344	3,804
			1982	4,147	1,875	6,022
			1983	4,149	1,873	6,022
4,624,293	1,319,323	5,943,616	1989	4,149	1,873	6,022
4,706,000	1,088,000	5,794,000	1993	4,149	2,151	6,300
4,668,000	1,265,000	5,933,000	1994	4,420	2,193	6,613
4,516,000	1,286,000	5,802,000	1995	4,420	2,198	6,618
4,598,000	1,319,000	5,917,000	1996	4,436	2,235	6,671
5,064,000	1,387,000	6,452,000	2003	4,410	2,235	6,645
4,936,000	1,798,000	6,734,000	2004	4,433	3,164	7,597
5,085,000	1,848,000	6,932,000	2006	4,433	3,164	7,597

Table-2 SRS Population and Sample Units

a Source: SRS Annual Reports. After the first report for 1969-70, population figures for the sample area were not provided in the annual reports until, 1989.

b Years for which there was no change in number of sample units with respect to previous year, are skipped in this table. For example, total sample units remained at 3722 from 1971 until 1975.

Registration work in new sample clusters is preceded by a base-line survey to obtain usual resident population of the sample area. Then, a resident part time enumerator continuously enumerates births and deaths in each of the sample village or urban block. An independent six monthly retrospective survey is done by a full time supervisor. Unmatched and partially matched events are re-verified in the field. Monthly reports are held at the state level for six months for incorporation of results from the retrospective surveys. These reports are then sent to the RGI office in Delhi, for tabulation, analysis and publication at the national level.

Main publication of the SRS is the Annual Report, which provides annual estimates of (a) population composition, (b) fertility, (c) mortality, and (d) medical attention at the time of birth or death (Table-3). In the 1970s, early years of the SRS, annual reports for more than one year were combined, for example, 1970-75, 1976-78, and 1979-80. From 1981 onwards, annual reports for each years have been published separately. The annual reports broadly consists of, (a) the summary chapters, and (b) the detailed tables. The first chapter of each annual report introduces the basic structure, sample design, organisation, flow of returns, and estimation procedure. Until 1988, statement-A in this chapter gives the number of sample units, by rural - urban area in each state and union territories. From 1989, statement-A included the absolute sample population in addition to the sample units. In 1993, the identification of this "Statement-A" was changed to "Statement-1". The states and union territories were grouped together. Presentation of states was revised in 1993, grouping them as major states and smaller states. The All India figures were brought up to the top row, instead of the bottom row as in the past. From 1993, the population figures were rounded to nearest 000. This statement allows for computation of SRS population by age sex groups with help of the % age distribution statistics, and then number of deaths by age sex groups with help of the age sex death rates. Chapters 2 summarises the population composition, with statements of population distribution by broad age groups. From 1991, this chapter includes cross tabulation of population by marital status and estimates of female age at marriage. Chapter-3 presents the various measures of fertility, and chapter-4 provides the measures of mortality. During the 1970s, all of the principals results, namely, population composition, fertility and mortality indicators were presented in chapter-2. Chapter-3 in some reports in this period contained abridged life tables, which have since been moved to a separate SRS analytical

series. Chapter-4 of the 1970-75 report summarised an evaluation regarding completeness of death registration by the SRS. Subsequently, evaluation reports have been published separately (RGI, 1982, 1984a-b, 1988). Cross tabulation variables in the summary statements may vary according to contemporary perceptions and policy makers' interest. For example, the broad age groups used until 1990 were 0-14, 15-49, and 50+ years. From 1991, the broad age groups were expanded to 0-4, 5-9, 10-14, 0-14, 15-59, and 60+. In 1994, another two broad age groups were added, namely, 15-64, and 65+ years. Statements on effective age at marriage, and distribution of population by marital status, reflects Government of India's concern for fertility control.

Table-3: Overview of demographic statistics from the SRS

Information	Available Statistics	Location in Annual Reports			
Population distribution	Population by 5 year age sex groups 0-4, to 70+ until 1994, and to 85+ since 1995	Table-1 in all Annual Reports			
Fertility	Population by Marital Status	Available from 1992 as Table-2.			
	Age Sp. & Marital Fertility Rates	Table-3 since 1993. Earlier Tables 2-4.			
	Age Sp. Fertility Rates by Education	Available from 1996, as Table-4.			
	Birth order and interval wise distribution of births	Available from 1990. Tables 4, 5 & 6 from 90-95, and Tables 5, 6 & 7 since 1996.			
Mortality	Age Specific Death Rates by 0, 1-4, and 5 year age groups from 5-9 until 70+ 0r 85+	Table-8 since 1996. Earlier table 4, 5 or 7.			
	Mort. Indicators: Crude Death Rate, Child mortality, IMR etc.	Table-9 since 1996. Earlier, 3, 4, 5, 8 or 9.			
	% Distribution of deaths by age	Since 1997, Table-10.			
Access to	Medical Attention at Birth	Statements 25, 30, 31, 34, 35, 38, 39 or 40			
Med. Care	Medical Attention at Death	Statements 42, 44, 47, 48, 51, 53, 55,56 or 57			

The "Detailed Tables" section of the annual reports contains population distribution, fertility and mortality estimates by five year age groups. The cross tabulation variables in the detailed tables are modular and consistent over time. For example, the population and mortality tables use five year age groups, from 0-4 to 65-69, and 70+ for all years. From 1996, 70+ group was expanded into five year age groups up to 85+ years. From 1992, this section of the annual report has been erroneously labelled as "Appendix: Detailed Tables". Actually, the detailed tables in SRS annual reports are the most valuable, as they are amenable for many kinds of analytical work, including time trend analysis, computation of life tables etc. Detailed tables in the annual reports give estimates of age specific fertility rates, and age sex specific death rates for bigger states having more than 10 million people. Estimates for smaller states and union territories are made on the basis of data for three consecutive years. For each state, SRS provides estimates for rural and urban areas. Recently, starting with the 2004 annual report, the SRS is giving estimates of mortality indicators by the NSSO natural divisions within the major states. The National Sample Survey Organisation (NSSO) natural divisions are contiguous group of administrative districts having similar geographic features, rural population densities, and crop-pattern (NSSO, 2001). But estimates for districts and smaller areas are not available from SRS. Some statistical tables like the population composition, fertility and mortality indicators have been published by the SRS continuously from its beginning. Subsequently, additional tabulations and new statistics were added in response to emerging requirements. For example; tables showing distribution of births by birth order and birth interval were, added from 1990. Population distribution by marital status, were added from 1994. Tables showing fertility by educational status of women was added from 1996. The new tables have usually been inserted to retain functional contiguity of tables. As a result table numbers in the annual reports, for the same statistic have changed over time, except for table-1 which has consistently presented the population composition in all annual reports of SRS, so far. Table-3 shows the time series of table numbers for the respective demographic indicators.

SRS bulletins, expected half yearly, were meant for quick release of key fertility and mortality indicators, such as crude birth rate, crude death rate, and IMR. However, publication of the bulletin has not been regular. SRS Analytical Studies series usually provides abridged life tables by sex and residence for India and major states estimated from the SRS mortality statistics. In addition, the analytical series report 1 of 1971, which, brought together IMR estimates for India from 1900 to 1950 is an useful reference for study of long term time trend of infant mortality in India. Occasionally, special surveys are conducted in SRS areas to inform contemporary policy concerns. For example, a comprehensive fertility survey schedule was canvassed along with the half-yearly survey for 1972 (RGI, 1976). Comprehensive surveys on Infant and Child Mortality was conducted in 1979 (RGI, 1980) and 1984 (RGI, 1989).

COMPLETENESS OF REGISTRATION OF VITAL EVENTS BY THE SRS:

Several evaluations of the SRS have been made, both inhouse by the RGI, and other authors. While many of these studies used analytical methods, some of the evaluations by the RGI were based on intensive inquiry of a sub-sample (Table-4). Both direct and indirect estimates showed that the incidence of under registration of births and deaths were within the tolerable range of up to 10%. However, all these evaluations of the Indian SRS were done for the period in 1970s and 1980s. The Registrar General has not taken up any direct or indirect evaluation study of the SRS during the 1990s and after. As a result, these old evaluations continue to be cited as evidence of completeness of registration of vital events by the SRS. For example, the WHO-HMN chapter¹ on issues in health information cites the indirect estimate by Bhat et al. (1984) to say that "the SRS has been shown to have attained a high level of completeness within sampled areas".

¹(http://www.who.int/healthmetrics/documents/hmnissue_measuringand-monitoring.pdf)

Dates	Sponsors	Study Design	Findings	Reference
1970 - 1975	RGI	Indirect estimate (Brass 1975).	6% under reporting of adult deaths.	RGI, 1982
1971 - 1976	NRC - CPD (USA)	Indirect estimate (Brass 1975, Preston & Coale 1980)	10% under reporting of deaths.No evidence of significant interstate variations. Excludes Bihar & West Bengal for poor data quality.	Bhat et al. 1984
1978	RGI	Indirect estimate (P/F Ratios, UN, 1983 Ch-II)	6% under reporting of births. State underestimates in 1978 ranged from <1% (Gujarat) to > 17% (Karnataka).	RGI 1984 a-b; Swamy et al. 1992
1980 - 1981	RGI	Direct estimate based on intensive inquiry of 10% sub-sample.	3% under estimation of birth rate, and death rate. State underestimates around 1% (Gujarat, Haryana & Madhya Pradesh) to 11% (Karnataka).	Grover 1988; Swamy et al. 1992
1985 - 1986	RGI	Direct estimate based on intensive inquiry of 10% sub-sample.	State underestimates, <1% (Andhra Pradesh, Bihar, Gujarat, Kerala, Madhya Pradesh, Maharashtra, Orissa, and Tamil Nadu) to > 3% (Assam & West Bengal).	Swamy et al. 1992
1972, 1978, 1982 & 1988	RGI & EW Ctr	Indirect estimates of total fertility using; Palmore (1978), Gunasekharan and Palmore (1984) and the Rele (1967, 1987) methods.	SRS adjusted estimates very good, but interstate differences exist, particularly for the years prior to 1975. The estimates are good for 10b out of the 17 study states. In case of Himachal Pradesh, Orissa, and Tamil Nadu, estimates prior to 1975 were too low. In Bihar and Rajasthan, SRS estimates of fertility were higher. State level adjusted estimates are more accurate for 1985-86.	Swamy et al. 1992
		Indirect estimates of life expectancy using four methods including Gunasekaran, Palmore and Gardner (1981); and Rele-Palmore (1992).	Indirect estimates of mortality usually higher than the SRS estimates. SRS may be overestimating mating mortality. In recent years (1988) SRS and indirect estimates converge for most states. The only exception was Punjab in 1988, where SRS may be underestimating mortality.	Swamy et al. 1992
1978 - 1992	IIPS, & EW Ctr,	Comparison of SRS with NFHS fertility estimates.	At least 10% under registration of births.	Narasimhan et al. 1997

Table-4: An Overview of Evaluation Studies on Sample Registration System in India

EW Ctr = East West Center, Hawai, Honolulu, USA ^b These are AP, Assam, Gujarat, Haryana, J&K, MP, Maharashtra, Punjab and West Bengal. So an important question is, whether the high level of completeness achieved by the SRS during the 1980s has sustained since then. Hence, completeness of adult death registration by SRS for each year from 1990 to 2007 was indirectly estimated by the Preston and Coale method (Preston, Coale and others, 1980) for all India and four selected states, namely, Andhra Pradesh (AP), Maharashtra (MH), Orissa (OR), and Uttar Pradesh (UP). Selection of only four states was arbitrary, in view of time constraints. Details of methodology, for estimation of completeness of death registration with respect to the underlying population, is also described in the United Nations Manual X (UN 1983 pp130-139)².

Two ratios are used by the Preston and Coale method to facilitate interpretation of the nature of data and identification of the completeness estimate. These are:

 $\widehat{C} = \frac{Population \ derived \ from \ distribution \ of \ deat \mathbf{h}s \ by \ age}{Corresponding \ count, i.e. \ actual \ population}$ Preston, Coale and others (1980) use the relationship between the number of deaths that a population at an age say a will experience at each age above it and the number of current deaths recorded at each age above age a. A cohort now at age a will experience deaths in future at different ages above a till the last person in the cohort dies. If we could look into the future, count the deaths experienced by the cohort at different ages, and sum them up, the result would add up to the same number of people as we have in the cohort now at age a. In case of a stable population, we can estimate the number of deaths likely to be experienced by this cohort in future, from our knowledge of the current incidence of deaths at ages above a and the population growth rate. Preston and Coale use this relationship to derive the size of population in each group from the current deaths at that age group and higher and the population growth rate. Specifically, where N(a) is the number of persons at age a in a stable population and D(x) is the number of current deaths at age x:

$$N(a) = \sum_{x=a}^{\omega} D(x) e^{G(x-a)}$$

The above relationship holds within a small margin of error for populations that are approximately stable i.e. gradual decline in mortality and recent changes in fertility. The Indian population would, by and large, satisfy the approximately stable population criteria. To estimate the deaths in the open age interval, the Preston, Coale and other's method requires choice of a model from the four (West, South, North and East) families of model life tables. For this study, India's population was assumed to closely resemble the West family. This computational decision is based on a comparison, using an index of dissimilarity, of the age composition of Indian population with that of the respective model life table families.

²Completeness of death registration (C) is the proportion registered of actual deaths; which is same as the ratio of registered deaths to actual deaths. This proportion is estimated by the ratio of population derived from the distribution of registered deaths by age group and the enumerated population in corresponding age group.

 $5\hat{N}x$ _ Estimated population in age group x to x+5

 $\frac{1}{5Nx} = \frac{1}{Enumerated population in age group x to x+5}$

5Nxhat/5Nx : ratio of population in 5 year age groups

 $\frac{\hat{N}_{x-70}}{N_{x-70}} = \frac{\textit{Estimated population from age x to 70}}{\textit{Enumerated population from age x to 70}} \cdots$

5Nhatx-70/Nx-70 : ratio of cumulative populations

The first ratio of populations in five year age groups (5Nhatx/ 5Nx) is sensitive to age misreporting. The second ratio of cumulative population upto age 70 (Nhatx-70/Nx-70) is not very much affected by age misreporting. So the ratio of cumulative populations gives us a more consistent estimate of completeness of death registration with respect to the enumerated population.

Note that this estimation would require knowledge of the population growth rate (r). However, the method allows us to start with a provisionally chosen growth rate and then iteratively arrive at the growth rate consistent with other assumptions about the population. The intercensal growth rate is a natural candidate for the provisional estimate of the growth rate. Best value of the growth rate r is the one that produces the most consistent set of completeness ratios across all age groups. In this analysis I have arrived at the iterated growth rate by minimising the slope of a line fitted to the estimated completeness for age groups 10-14 to 65-69 years . In case, the estimated completeness values for extreme age groups showed substantial difference from the estimates for middle age groups, I have relied on lines fitted to the estimates for the middle age groups (20-24 to 50-54 years). The iterated population growth rate is then a by product of this estimation. Consistency of the iterated growth rate over a short period of time will be added evidence about validity of the assumptions about the population and reliability of the completeness estimate (Table-5).

Iterated exponential growth rates (r)				Year	Estimated completeness					
AP	MH	OR	UP	India		AP	MH	OR	UP	India
0.0160	0.0236	0.0223	0.0193	0.0219	1990	0.67	0.68	0.83	0.79	0.77
0.0186	0.0241	0.0217	0.0206	0.0223	1991	0.82	0.83	0.89	0.73	0.79
0.0166	0.0244	0.0224	0.0219	0.0253	1992	0.71	0.82	0.88	0.90	0.99
0.0191	0.0251	0.0226	0.0241	0.0243	1993	0.75	0.82	0.99	0.93	0.87
0.0237	0.0252	0.0223	0.0245	0.0245	1994	0.90	0.87	0.93	0.96	0.91
0.0243	0.0230	0.0228	0.0231	0.0251	1995	0.88	0.77	0.98	0.87	0.91
0.0217	0.0236	0.0206	0.0208	0.0247	1996	0.80	0.85	0.88	0.85	0.89
0.0159	0.0130	0.0194	0.0209	0.0243	1997	0.52	0.45	0.66	0.60	0.86
0.0210	0.0222	0.0212	0.0250	0.0255	1998	0.82	0.83	0.97	0.99	0.93
0.0211	0.0208	0.0200	0.0255	0.0227	1999	0.76	0.77	0.84	0.97	0.78
0.0206	0.0204	0.0212	0.0253	0.0223	2000	0.80	0.77	0.91	0.94	0.78
0.0186	0.0235	0.0223	0.0267	0.0236	2001	0.70	0.99	0.99	0.95	0.80
0.0208	0.0224	0.0215	0.0259	0.0236	2002	0.76	0.80	0.84	0.93	0.81
0.0212	0.0212	0.0245	0.0276	0.0256	2003	0.76	0.78	0.98	1.04	0.90
0.0208	0.0204	0.0198	0.0244	0.0242	2004	0.67	0.67	0.89	0.90	0.83
0.0226	0.0197	0.0182	0.0255	0.0245	2005	0.69	0.69	0.81	0.89	0.78
0.0226	0.0210	0.0208	0.0265	0.0245	2006	0.70	0.75	0.84	0.92	0.78
0.0179	0.0201	0.0214	0.0283	0.0244	2007	0.58	0.72	0.89	1.05	0.82

Table-5: Completenessa of death registration by the Indian SRS from 1990-2007.

^aBased on Preston and Coale and Brass Growth Balance methods for all persons (i.e. both females and males). Total population, age distribution of population, age specific death rates data taken from respective SRS Annual Reports.

^bAP=Andhra Pradesh; MH=Maharashtra; OR=Orissa; UP=Uttar Pradesh; IN=All India

The completeness estimates presented in table-5 suggest that registration of deaths within sample areas, by the SRS has worsened during 1990s up until 2007. The all India estimate of SRS completeness range from 77% to 99%. Only in five out of 18 years, the SRS could achieve 90% or better completeness of registration. For six out 18 years, all India completeness of death registration by SRS was less than 80%. Significant interstate variations appear to exist. Estimates of four selected states show that completeness of death registration by SRS appear to have been better in case of Orissa and UP compared to Andhra Pradesh and Maharashtra. Completeness was less than 80% for 13 years in case of AP and 11 years in Maharashtra over the 18 year study period. Uttar Pradesh achieved 90% or more completeness for 10 years and Orissa did so for seven years.

OVERALL QUALITY AND USEFULNESS OF THE INDIAN SRS:

The Assessment framework for vital statistics developed by the Monitoring of Vital Events (MoVE) writing group of the Health Metrics Network (HMN) in the World Health Organization (WHO) includes many aspects affecting usefulness of vital statistics, in addition to completeness of registration (Mahapatra et al, 2007). I examine characteristics of the Indian SRS along these dimensions, based on available data and my personal experience in accessing and using the SRS.

ACCURACY

Coverage, completeness and incidence of missing data are three key contributors to accuracy of estimates produced by any statistical system. Although, the SRS covers about 0.6% of India's population, its representative character allows for estimation of vital statistics for the country and major states. Completeness of registration of events has been, by and large, around 90% or more upto 1980s. Interstate differences also narrowed down by mid 1980s. However, completeness appears to have worsened during the 1990s and after. Interstate differences in completeness appear to have widened also. The annual reports describe system of gathering and reporting of data. But no specific information is reported about missing data. It is generally believed that missing data in SRS is rare. However, it will be useful to start documentation of missing data elements, such as age, sex of vital events. The annual reports should include a table showing the number of births and deaths for which age or sex information was not available, and how the events were treated through the tabulation process. In case there is no missing data, the report should make a positive mention of the fact.

RELEVANCE

Routine tabulations by the SRS are adequate (See table-3). Population composition and age specific death rates are available in five year age groups. Distribution of live births, by mothers' age, birth –order and -interval, are provided in a consistent format over the years. However, the SRS cannot provide small area statistics at the district and sub-district level. State level estimates are available only for major states. Recently, SRS sample size has been increased to allow for IMR estimates by NSSO natural divisions, which are usually a group of districts within a state. But the sample size will have to increase enormously, if district level estimates are to be produced.

COMPARABILITY

Definition of terms, administrative guidelines and data collection methods of the SRS are consistent over time, allowing for comparability of over time. Similarly, uniform definition of terms, administrative guidelines and data collection methods across the country, makes the SRS statistics comparable across space.

TIMELINESS

Timeliness has two important sub-dimensions, namely, (a) promptness (production time), and (b) regularity. The SRS Annual Reports do not show their publication date, to allow for direct computation of production time. However, publication date can be inferred from the date shown in the preface written by the Registrar General, India for each report. The actual publication date would be later than this date. For example; preface of 1999 report is dated Jan 2002. The report was published in 2003 as can be inferred from the printing date shown on the back cover. Thus the actual production time would be more than what is estimated here, at least by about six months. The median production time from inception of SRS till production of latest annual report (2007) is about 2¹/₂ years. The production time was $6\frac{1}{2}$ years in the 1970s, $2\frac{1}{2}$ years during 1980s, 2 years during 1990s and about 22 months for the years 2000 - 07.

The SRS brings out a half yearly bulletin which is published in April and October, usually within about six to nine months. For example, as of Jan 2010, the latest SRS Bulletin available at the RGI website, is for October, 2009. The bulletins contain selected aggregate vital statistics such as infant mortality, birth and death rates by rural, urban area but no disaggregation by age or sex. However, sometimes, scheduled issues of the bulletin may not be released at al. For example; no bulletin is listed at the RGI website for October 2005, and April, 2007-09. Regularity in publication can be measured by the standard deviation of production time. If the production is very regular the standard deviation of production time would tend to be zero. On the other hand, if publication is irregular, the variance of the production time will increase. The standard deviation of production time from inception till the 2007 report is about 32 months. If we ignore the 1970s, when SRS started, the standard deviation of production time improves substantially. The standard deviation was about 5 months in 1980s, two months in 1990s, and seven months for the period 2000-07.

Although, production of SRS Annual reports has been mostly regular, there is some scope for further improvements. For example; in the recent past, two annual reports were lumped in a single year, 1997 & 98 published in 2000, 2001 & 02 reports published in 2004, 2004 & 05 reports released in 2006. No report was released in 2001 to 2003. The SRS tabulation and production calendar should be streamlined for release of an annual report every year.

ACCESSIBILITY

Accessibility of SRS reports can be characterised by its performance in terms of (a) the media of publication, (b) availability of metadata, and (c) the quality of user service. Annual reports are available in print form only. The half yearly bulletins are available in print as well as portable document format (pdf) files through the Internet since April 1999. But SRS data sets are not released, although the RGI has made significant progress in other areas of its operation, for example, release of census data sets through CD Rom. The annual reports could also be released in pdf file format over the internet.

From 1987, the SRS annual reports included a "Glossary" at the end of the report, containing definition of the various statistics provided in the reports. From 1996, the "Glossary" was moved to the front pages of the report and relabelled as "Definitions". The first chapter of each annual report give details of basic structure, sample design, system of data collection and definition of terms. However, specific metadata are difficult to find. The population figures in statement- A or 1 are not available by sex. From 1993 the RGI is rounding the population figures to nearest 000. This reduces scope for consistency checks and indirect estimation of the accuracy of SRS statistics. Hence, population count should be reported by age sex groups, as it is, without any rounding. The second annual report (RGI, 1971) carried information about the number of reporting units from out of the total sample units. However, this information has been dropped from subsequent reports. It will be desirable to reintroduce this information, as it will be relevant, even if reports from all sample units are received. A positive statement of such a fact will provide data users the required input for assessment of data quality. Hence the SRS Annual Report should include a table similar to the "% of monthly returns received" in the "Vital Statistics of India Based on Civil Registration System", published by the RGI.

User service, needs further improvement. The sale counter at RGI's head office in Delhi delivers reports across the counter

and also responds to requests over post. Regional sale counters in state capitals do not usually stock all publications. There is scope to improve responsiveness by outsourcing distribution and sale functions to private agencies. The RGI Library at RK Puram Delhi does not have a reference set of all SRS publications. The indexing, cataloguing and retrieval services of the RGI library needs to improve. A comprehensive list of publications such as (a) SRS annual reports, (b) SRS bulletins, (c) SRS analytical studies, (d) occasional papers, and (e) SRS mimeographs and working papers, released by the RGI from inception of the SRS, and updated from time to time will be helpful.

SUMMARY AND RECOMMENDATIONS:

Overall the Indian SRS has been a reliable and trusted source of fertility and mortality statistics for the whole country and major states. Half yearly bulletins containing aggregate vital statistics are usually available quickly. SRS Annual reports containing detailed statistical tables and some analysis are released after a production time lag of about two years. Definition of statistical concepts and data gathering process are consistent over time and uniformly implemented all over the country. After initial difficulties during the 1970s, the SRS achieved 90% and better completeness of registration during the 1980s. Both direct and indirect evaluations during this period contributed to consolidation of the system. These old evaluations continue to be cited as evidence of completeness of registration of vital events by the SRS. There is evidence to suggest that completeness of registration might have deteriorated during the 1990s and after. Significant interstate differences appear to have emerged. Hence, evaluation studies at regular intervals should be built into the system. Both direct and indirect estimation of completeness should be taken up. A pluralistic evaluation framework consisting of in-house evaluations by the RGI and studies by independent researchers is very much required. There is also scope to improve the metadata content of SRS annual reports by expanding the statement of populations to include details by sex, reporting of the population figures to the last digit, and incorporating standard tables on incidence of missing data. There is further scope to improve accessibility of SRS by publication of the annual reports in portable document format, and eventual publication of the SRS data sets in appropriate electronic database formats. User service may be improved by outsourcing the publication and distribution functions and identifying a network of libraries to act as vital statistics document repositories.

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IMPROVING COVERAGE AND COMPLETENESS OF VITAL STATISTICS – A KENYAN EXPERIENCE

JOYCE MUGO

DIRECTOR CIVIL REGISTRATION

BACKGROUND

Registration of births and deaths was introduced for the first time in Kenya (The East Africa Protectorate) in 1904. At the time, the regulations only applied to Europeans and Americans. However, in 1928, parliament enacted the Births and Deaths Registration Act (Cap 149) to provide for the Notification and Registration of births and deaths in Kenya. At that time, the Act provided for compulsory registration of births and deaths of Europeans, Americans and Indians throughout Kenya. For all other races, it provided for registration of deaths that occurred within municipalities only.

Compulsory registration to other areas and communities was extended in stages beginning with Nairobi and Nyeri Districts on 1st March, 1963 until the whole country was covered on 1st September, 1971. this meant that all births and deaths which occurred before then were not registered. Registration of births and deaths was a section in the Registrar General's office until 1989 when it was made a fully fledged department and administratively moved to the office of the President. During the reorganization of Government in 2005, it was moved to the Ministry of state for Immigration and Registration of Persons, where it is currently. A community based civil registration programme was launched in 1982 covering some few Districts i.e. Muranga, Nyeri, Kirinyaga and Kakamega. This has been extended to all districts in Kenya early 2009

PROCESS OF REGISTRATION

Civil Registration activities in Kenya are carried out by the department of Civil Registration whose core mandate is to ensure registration of all births and deaths occurring in the country. The department also has a co-ordination role of registration agents and other partner agencies. The two lines/ key registration Agents are Ministry of Medical Services and Public Health and Sanitation and the Department of Provincial Administration having the registration function of births and deaths occurring at home and co-ordination of the registration Assistants (Chiefs& Assistant Chiefs)

MINISTRY OF HEALTH

The Ministries of Health have personnel in all Health institutions. They register births that occur in Health Institutions with maternity facilities

Births registration Personnel:-Midwives, Nurses and Medical attendants record the births in the delivery register kept in the maternity ward. This ensures capture of all births (alive or still) and neo-natal deaths occurring in that Health facility. The information on recorded events is transferred to the register of birth which is a prescribed form. Some of the prescribed particulars recorded include:- Name of child, gender, nature of birth, type of birth, date of birth, place of birth, age of mother, marital status of mother, previous births, capacity of informant/ registration assistant. The Birth forms (B1) is filled in carbonated duplicate and are submitted to the District Civil Registrar Monthly. Gaps exist where some events go un notified which necessitates hospital audits to be done by the District Registrar and Hospital staff to compare numbers received in his office and those recorded in hospital.

Deaths: - Deaths occurring in hospitals are recorded by medical staff with cause of death certified by the doctor attending the patient before death

- Post-mortem is done on bodies from unnatural causes of death. The duly filled and signed form is then submitted to the district registrar for compilation numbering and for further analysis at department statistics section
- Suicidal deaths do not have their own category but are categorized with other causes.

N/B Most of these unnatural causes have to be cleared by the police to rule out foul play. In 2008, 66.8% births and 50.7% deaths occurred in Health Institutions.

PROVINCIAL ADMINISTRATION

The structure of Provincial Administration at the lower level is as below:

District Commissioner	>	District
District Officer	>	Division
Chief	>	Location
Assistant chief	>	Sub location

Provincial administration registers births and deaths occurring at home. The Assistant chief is the registration agent in the sub location, the smallest administration unit of about 100 households. He ensures all births occurring in his sub location are registered by use of open air meetings (Barazas) and attends burials and sensitize the community on the legal compliance that there should be no burial without a burial / disposal permit.

- The information on death registers D2 for deaths occurring at home is filled by registration agent, informants/relatives and Registration assistant who report the symptoms of the deceased before death.
- The Assistant chief D2 form contains a few common causes of death where he chooses from but which is not comprehensive. There is also a section of unnatural causes e.g. suicide, drowning e.t.c where the police have to carry out preliminary investigations and then signs the record for the Registration Assistant
- Particulars pertaining to the deceased are:-name of deceased, age, place of death (sub location), usual residence, and causes of death and capacity of informant among others.
- All the records are then submitted to the District with a dispatch form to ensure that all serialized issued forms are received back by the registrar for accountability and further analysis

-See D2, B1, D1 forms attached.

STAKEHOLDERS / PARTNERS IN CIVIL REGISTRATION

Despite the fact the efforts of the two key registration agents to capture all births and Deaths and especially those occurring at home, some births still go un registered due to religious and cultural beliefs which prohibit their followers to attend hospitals or attend to dead bodies, Muslims who burry the dead on the same day sometimes without a permit for burial, Ignorance and laxity of benefit of registration of events by the public.

To enable the department capture these events, it has partnered with other stakeholders, consumers of her products to help in advocacy and publication for registration.

These Government agencies include the Department of children and services who require for birth and death certificates when assisting the Orphans and the vulnerable children (OVCs) in their Programmes, the Ministry of Education on admission to all institutions of learning.

Department of National Registration to ask for birth certificates, before issuing of Identification cards at the age of 18 years.

The Ministry of health has community health workers in charge of 50 households. These help to identify home births and liaise with the provincial administration in such areas to capture all births.

Traditional birth attendants and retired skilled midwives, who conduct births also liaise with Assistant Registrars for registration. Village elders, also ensure that all deaths occurring at home are properly notified.

Health Institutions also inform mothers who take their children for immunization of the importance of registration especially those born at home. The immunization card has been re- designed to comprise of the information of expectant mother through delivery and the same is used as a child welfare card. This card has a slot for birth notification number to ensure that although the birth was notified irrespective of place of occurrence.

CHALLENGES TO REGISTRATION

- Low awareness of the registration benefits to the public.
- Low demand of civil registration products- statistics, certificates by consumers. The department has not been able to attract more consumers for her products to expand the demand base.
- Lack of political will- Kenya is divided by political constituencies from where funds for bursary are disbursed but the members of parliament who are the patrons do not enforce the registration requirements.
- Difficult terrain- some districts in the north eastern Kenya are too vast for the parents to report events to their Registration assistants on time and this also hinder constant monitoring by the registrars who do not have vehicles compliant to such terrain.
- Lack of enforcement of the act governing registration of the events. The cap 149 of the laws of Kenya provides that anyone with knowledge of occurrence of a birth should report to the appropriate authority before a period of six (6) months and if not he/she is reliable to a fine of kshs 500 or 6 months imprisonment or both. Although it's not punitive enough it has not been done against anyone.
- Low literacy levels of some registration agents who are recruited from the community.

CHALLENGES FOR THE VITAL STATISTICS SECTION

- Many births occur at home and therefore go unnoticed even after six months. The personnel filling the death registers lack training on causes of death/verbal autopsy.
- There are no trained personnel on coding of causes of death
- Lack of motivation/ incentive for the registration agent when submitting forms to the district registrars.
- Inadequate funding for building statistical capacity of the staff.
- Low funding for monitoring and supervision personnel
- There is no structured monitoring and evaluation mechanisms to capture the gaps in registration

MILESTONES IN DEALING WITH CHALLENGES

 The Ministry of Immigration and Registration of Persons is in the process of establishing a national population register. A one stop shop for personal information regarding each Kenyan citizen. It has established a Department of Integrated Population registration Services where all births form the database.

- A community mobilization system is operational in all districts in Kenya where community leaders are trained to own the registration processes through faith based organizations social groups', Non-Governmental organizations e.t.c
- Multi-sectoral approach where stakeholders use their comparative advantage to raise awareness mainstreamed in their core functions e.g. Ministry of Education and its forum of parents, teachers and students, plan international on children charitable programmes,
- Children's department on cash transfer programmes
- Ministry of health during national and regional immunization programmes
- Civil registration has a structure that stretches from regional supervisor based at the Department headquarter who is in charge of a province – provincial co-coordinator, in charge of districts in the province and district registrars in charge of the district staff.
- Regional supervisors visit the regions quarterly and provincial coordinators hold meetings quarterly with District registrars to deal with registration matters and how to improve coverage
- A full fledged statistics section dealing with: compilation, analysis, dissemination and storage of vital data.
- Automation of 1.5 million records out of 5 million manual records targeted 1992-2008. The rest of the manual records need automation to enhance retrieval of records on demand.
- The department has developed an operations manual and a registration policy to facilitate ease of registration issues nationwide (at bill stage)
- Employment and Deployment of personnel with statistical skills to man statistics section
- Capacity building for registration agents by Districts
- Publicity through public service week which is a forum where the public interact with Registration Officers.
- Interactive radio shows on Fm stations where the public call in live for question and answer sessions on registration. This is going on in coast and some parts of central provinces.
- Use of short message service to raise any concern and give feedback to the Department.

RECOMMENDATIONS AND WAY FORWARD

- Continuous capacity building for the registration agents
- Strengthening of the co-ordination, monitoring and supervision functions of the department
- scaling up of advocacy and publicity on registration
- Creating Nationwide demand for the civil registration products by relevant organizations
- National social security fund (NSSF)
- National hospital insurance fund
- School enrolment and Examination Registration
- Mopping up of whole families and communities through field registration
- Automation of vital records from the source e.g. Health records and provincial administration.
- Training registration personnel and agents on verbal autops
- A concerted effort from all sectors of life will ensure raised coverage and completeness of registration records

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DEMOGRAPHIC SURVEILLANCE SYSTEMS

PETER KIM STREATFIELD, PHD AND NURUL ALAM PHD, MATLAB HEALTH AND DEMOGRAPHIC SURVEILLANCE UNIT,

PUBLIC HEALTH SCIENCES DIVISION, ICDDR, BANGLADESH

According to the In-Depth Network of Demographic Surveillance Sites (www.indepth-network.org), a true DSS must collect data on all births, deaths, in-migrations, and out-migrations in order to maintain an accurate estimate of the surveillance population. The definitions of births and deaths are clear enough, but the definition of in- and out-migration varies across sites, usually using the old UN definition of at least six months stable status (in- or out-), but many now changing to "intention to migrate". As with any system, a DSS has various disadvantages (Cons) and advantages (Pros).

CONS:

1. EXPENSIVE IN DOLLARS AND IN MANAGEMENT (DATA AND PERSONNEL) REQUIREMENTS

Matlab costs about \$2 per person per year of surveillance information, and cost is determined by travel time, numbers of households, frequency of visits. The Matlab DSS has only survived by collecting more than the minimum information and making itself into a platform for other mostly non-demographic health studies. These have increasingly been clinical trials for vaccines (e.g., two Rotavirus trials are running now) and health interventions (IMCI for child health, and others for maternal health, nutrition, arsenic, etc.). These studies are expected to contribute financially to the operating costs of the DSS.

What to do about high costs? We can reduce costs by reducing visit frequency. Some In-Depth sites visit annually, but this creates problems of recall, which affects different events differently. For example, with long recall periods, respondents are not likely to forget live births, but are more likely to forget early miscarriages or induced abortions, and cause of death symptom reporting deteriorates over long recall periods. Some take only a sample of households, but that creates other problems of representativeness, and sampling errors. Technology is not yet reducing data collection of processing costs to any extent. Use of PDAs and optical scanning does reduce data entry time, but not by as much as one might expect. Mobile phones greatly speed up error correction, and can improve data transfer from the field. But PDAs require more complex programming and have high memory demands for DSS databases in the field, compared to cross-sectional surveys, due to the longitudinal nature of the data.

2. UNCERTAINTY ABOUT REPRESENTATIVENESS.

No single area accounting for only 0.15% of the national population (like Matlab) can be representative. We need to know how it is different, and what biases that introduces. This apparent lack of representativeness has been a factor in limiting acceptability of Matlab research findings by Government (MOH). It is not such a problem for vaccine trials, but it is for social interventions, such as behaviour change, where they believe that the long and intensive ICDDR,B presence has already made the population more receptive to interventions.

To determine how representative a DSS site is (or is not), we can compare with national surveys, selected sub-national surveys, SVRP, censuses, other vital statistics. We can do comparisons of characteristics such as education, environment (W&S), economic activity, nutritional status, exposure to high impact diseases – malaria, TB, HIV, contaminated water, arsenic, etc., and try to project where we differ, and the impact of those differences.

For example, Ken Hill compared the BMMS-2001 age & sex specific mortality rates with Matlab rates and found good agreement. That was taken as an assessment of BMMS, but we took it in reverse as an assessment of Matlab DSS data also.

If a DSS area is rural, can we make any extrapolations about urban populations? Is the only solution (approach) to establish urban DSS as well? If so, what are the biases introduced by rapidly turning over slum populations, who are presumably at elevated mortality risks, compared to wealthier and more stable urban populations?

PROS:

1. COMPLETENESS OF EVENT REGISTRATION

Because of the longitudinal nature of the DSS, it is quite noticeable when a DSS resident dies. It is also noticeable when a woman is pregnant, at least by second trimester, unless she intentionally conceals the fact. Thus pregnancy outcomes are well recorded. The challenge is not so much in completeness, but in timely reporting. A substantial number of births (especially first births) take place at the natal home of the new mother, and this may be outside the DSS area. There are sometimes time lags in reporting these births, but they are usually caught because the pregnancy was noted earlier. Longer duration (e.g., 6 or 12 months) between household visits increases the risk of missing these external births, or indeed any births. There can be issues of missed early neonatal deaths never being recorded as live births, especially if the birth is outside the DSS area.

Other deaths can also be missed if the ill person left the DSS area for treatment, and never returned. There can be both lengthy lag periods before VA interviewing, and there can be problems to identify suitable respondents who were present at or around the time of the death to report symptoms.

2. WIDE VARIETY OF VARIABLES CAN BE COLLECTED FOR BETTER EXPLANATORY POWER

A system of repeated household visits means that additional information can be collected at relatively low cost. A recent survey was added, at virtually no additional cost, to determine the extent of recent floods as part of climate change impact monitoring. The installation of a weather station is now generating additional data for such studies at very low cost.

3. IDENTIFICATION NUMBERS

Use of ID numbers by al household members in the community and facilities in the DSS area permit monitoring of utilization and non utilization of health facilities, as well as tracing of patients, determining severity of illness conditions, etc.

4. REPEATED MEASUREMENTS ON SAME POPULATION OVER TIME

The longitudinal nature of the DSS data allows analyses of dynamic processes which are very difficult if not impossible to explore in cross-sectional studies. For example, a current study is estimating the impact of chronic non-communicable diseases among adults on driving households into poverty – this is using household economic (assets, employment, etc.) collected data over three decades in conjunction with illness histories.

To sum up, DSS systems generally do not miss significant numbers of births and deaths. There may be time lags in reporting, but if the household visit schedule is reasonably short (less than six months, as most ID member sites are), then completeness of coverage should be adequate.

To expand on some of the above discussion, the issue which creates the most problems for monitoring births and deaths in DSS sites is migration, because when demographic events occur within an observation window (that is, while waiting to see if an in-coming family will remain permanently in residence, or an outgoing family will remain out), then the status of those events is questionable, as they are not occurring to a regular DSS resident. Some sites use the traditional six months window, others have switched to a two month window, others are changing to "intention to migrate", especially in urban areas where selected populations, e.g., in slums, may 'turn over' (move on) very quickly.

The second focus of this paper is cause of death diagnosis, and this will now be discussed below.

CAUSE-OF-DEATH DIAGNOSIS

The issues affecting cause-of-death diagnosis in DSS sites fall under the following headings: personnel; respondents; and technical.

1. PERSONNEL

Ideally, physicians should be used for making cause of death diagnoses, but physicians usually want to save lives not record deaths. Our experience is that physicians find COD work boring and depressing, especially for premature deaths (e.g., children). Physicians are also relatively expensive, and Matlab with 1,500 deaths annually requires at least one full time physician for this work.

Training is an important issue. There are no solid training materials (there is Tendon from WHO, but it does not serve the entire purpose) combined with accreditation materials where physicians can be assessed in terms of their accuracy of diagnosis or replicability of diagnoses. This issue was brought home to the Matlab DSS when we used different teams of physicians to reviews 3,000 Verbal Autopsy questionnaires (WHO models with ICD-10) in 2003 and 2004. The resulting diagnoses were substantially different even based on the same cases and VA reports (see Alam et al., 2006: 65).

In that same exercise we used a very experienced Medical Assistant (MA) to review the same VA questionnaires as the physicians. Overall the MA tended to give more general diagnoses than the physicians, e.g., for neonatal deaths the MA often reported 'pregnancy or delivery complications' whereas the physicians gave 'birth asphyxia' for many of the same cases (ibid, 106).

2. RESPONDENTS

There is anecdotal evidence that some respondents misreport, either intentionally or unintentionally. For example, there have been cases of suicide reported by families for recently married young women(daughter-in-law), where homicide is suspected, often linked with non-payment of dowry by the bride's parents.

Circumstances surrounding a death may be misreported to avoid blame. For example, a child drowning death (now the leading single cause of child death in Matlab) can lead to blame on the mother if she attempted to rescue the child and it did not survive. Similar misreporting may surround abortion related deaths, and other sensitive events

Finally, as three out of our deaths occur not in a medical facility but at home, respondents often lack diagnostic information to convey a complete picture of symptoms and underlying causes. This is a particular problem with sudden deaths among the elderly. For this reason, more effort is needed to explore if the deceased had any recent medical or pathology tests at a medical facility, the results of which may assist a diagnosis.

3. TECHNICAL ISSUES

COD bias: Some sites rely simply on physicians' undergraduate medical training with a little specialized VA COD raining. This can introduce subjective biases at the level of individual physicians. Similar biases can occur at a collective level in regard to specific diseases. For example, in four decades Matlab has never produced a diagnosis of HIV or malaria, but when the recent symptom data are run through the InterVA algorithms (www.interVA.net), a number of such diagnoses are generated. Our physicians assume that the algorithms must be wrong, due to algorithms being designed around African COD patterns, but the algorithms could be correct.

Underlying and direct/immediate causes: even with widespread use of ICD-10 the interpretation of underlying and associated causes of death is still evolving. An example is maternal deaths where recent discussions at WHO are modifying the interpretation of causes like prolonged labour, as what really kills a woman with this condition is usually ruptured uterus triggering a fatal haemorrhage.

Computer Algorithms: One approach to reducing COD bias, and to save time and cost is the development of computer algorithms. Those such as InterVA (and InterVAM for maternal deaths) developed by Peter Byass and others at Umea University, Sweden, cover many causes, but not all. Additional causes are being gradually added. Johns Hopkins University has developed and tested such algorithms for child deaths.

COD generated by algorithms are very susceptible to the sequence of questions in the flow chart. For example, in the Bangladesh DHS 2004 child mortality COD analysis, malnutrition accounted for 3.6% of under 5 deaths because the cause malnutrition was ranked #9 in the question sequence. When malnutrition was placed at #6 in the question sequence (above rather than below ARI, diarrhoea, measles, serious infections and prematurity/LBW, malnutrition increased six-fold to 21.5% of under 5 deaths. The current development of the Symptom Pattern method (Murray and Lopez) is expected to contribute to resolving some of these problems of algorithms. This method requires a large proportion of deaths to be occurring in a medical facility such as a hospital. In Bangladesh and many other countries, this is not the case, where only 10-12% of deaths occur in a facility.

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ARMIN FIDLER

LEAD ADVISOR HEALTH POLICY AND STRATEGY THE WORLD BANK

An Austrian national, Dr. Armin Fidler joined the World Bank in 1993 and started to work in the Latin America and Caribbean (LAC) Region. In 2000 he became the Manager for Health, Nutrition, Population for the Europe and Central Asia Region. In 2008 Dr. Fidler was appointed Lead Advisor for Health Policy and Strategy in the Bank's Human Development Network at the global level.

Dr. Fidler holds a Doctor of Medicine Degree (MD) from the University of Innsbruck, Austria, a Diploma in Tropical Medicine and Hygiene from the Bernhard Nocht Institute, Hamburg, Germany and Master of Public Health (MPH) and Master of Science (MSc.) degrees in Health Policy and Management, both from Harvard University's School of Public Health. He also earned certificates in Management from the Harvard Business School and in Public Finance and Welfare Economics from the London School of Economics and Political Science.

Prior to joining the World Bank, Dr. Fidler served as Sub-Regional Advisor for the World Health Organization (PAHO/ WHO), based in Mexico and Central America after serving in the Epidemic Intelligence Service (EIS) at the US Centers for Disease Control and Prevention (CDC) in Atlanta, GA.

He was an advisor to the Austrian Minister of Health, Youth and Family and serves on the international advisory council for the Governor of the State of Vorarlberg, Austria. He serves on the Executive Committee and Board of the Global Alliance for Vaccines and Immunizations (GAVI), and represents the Bank at the Global Fund to fight AIDS, TB and Malaria.

ALAN LOPEZ

HEAD, SCHOOL OF POPULATION HEALTH UNIVERSITY OF QUEENSLAND, AUSTRALIA

Professor Alan Lopez is Professor of Medical Statistics and Population Health and Head of the School of Population Health at the University of Queensland. Prior to joining the University in January 2003, he worked at the World Health Organisation in Geneva, Switzerland, for 22 years where he held a series of technical and senior managerial posts including Chief epidemiologist in WHO's Tobacco Control Program (1992-95), Manager of WHO's Program on Substance Abuse (1996-98), Director of the Epidemiology and Burden of Disease Unit (1999-2001) and Senior Science Advisor to the Director – General (2002). He is also an Affiliate Professor of Global Health at the Institute for Health Metrics and Evaluation at the University of Washington.

He is a highly cited author whose publications have received worldwide acclaim for their rank in importance and influence in health and medical research (with over 10,000 lifetime citations). He has published over 200 peer-reviewed journal articles, books, letters and book chapters on mortality analysis and causes of death, including the impact of the global tobacco epidemic, and on the global descriptive epidemiology of major diseases, injuries and risk factors. He is the co-author with Christopher Murray of the seminal Global Burden of Disease Study (1996) which has greatly influenced debates about priority setting and resource allocation in health. His 2006 Lancet paper (lead author) with Murray and colleagues was listed among the 25 best publications in health and medical research worldwide in that year. Three of his Lancet papers with Murray have each been cited more than 1000 times.

He is the co-author (with Sir Richard Peto) of the Peto-Lopez method which is widely used to estimate tobacco-attributable mortality to support policy action. He, Sir Richard and others recently published a second (online) edition of their seminal book on Mortality from Smoking in Developed Countries. He was awarded the Leverhulme Prize (with Sir Richard Peto) by the Liverpool School of Hygiene and Tropical Medicine in 1998 for his contributions to epidemiology and international health.

Professor Lopez is on the editorial board of PLoS Medicine and Preventive Medicine, and co-Editor in Chief of Population Health Metrics. He is a member of the Wellcome Trust Population and Public Health Funding Committee (2007-2010), the WHO Expert Committee on NCD Surveillance (2009-2011), the US National Academy of Sciences Panel on Divergent Trends in Longevity (2008-2011), the Scientific Board of the Oxford Health Alliance Grand Challenges in Non-Communicable Disease (2006-2009), and was former Chair of the Health and Medical Research Council of Queensland. He was recently elected as a Foreign Associate Member to the Institute of Medicine of the U.S National Academies of Sciences.

PRASANTA MAHAPATRA



HON. PRESIDENT INSTITUTE OF HEALTH SYSTEMS INDIA

Dr. Prasanta Mahapatra, is Harvard alumni. He has Ph.D. in International Health Economics and Policy from the Harvard University. He was a Takemi Fellow during 1991-93. After his medical degree in 1977, Dr. Mahapatra practiced medicine and was a member of India's Central Health Service. In 1980 he joined the Indian Administrative Service. He has extensive experience in public health and public administration, including; Registrar of the AP University of Health Sciences, District Collector Nellore, Commissioner of AP Vaidya Vidhana Parishad, Faculty, Administrative Staff College of India, Director Institute of Health Systems, Principal Secretary, Women Development and Childwelfare. He has worked in the Planning Commission of India, and contributed to the mid term appraisal of the health sector in the tenth five year plan.

Dr. Mahapatra was one of the early members of the Harvard Burden of Disease unit. He worked with Dr. Christorpher Murray on the Global Burden of Disease estimation project, leading to publication of the GBD estimates in WDR 1993. Since then, he has contributed to the burden of disease studies. He is the author of the Andra Pradesh Burden of Disease study and has published work in various areas including, health state valuation, cause of death, health system performance assement, private health sector, civil registration systems, etc. He was the lead author for one of the four papers in the Lancet' Who-counts series (2007 Oct) on civl registration systems and vital statistics. Dr. Mahapatra was a key contributor to the WHO-HMN framework for assessement of vital statistics systems that includes various aspects affecting usefulness of vital statistics, in addition to completeness of registration.



JOYCE W. MUGO

DIRECTOR CIVIL REGISTRATION DEPARTMENT KENYA

Mrs J. W. Mugo joined Public Service in Kenya in 1980 after graduating from the University of Nairobi with a Bachelor of Arts (Government option) degree. She worked as a Registration Officer until 1984 when she was deployed in the Office of the President as an Administrative Officer. She rose through the ranks to the level of Under Secretary in 1997. In 2001 she was appointed Head of the National Registration Bureau Department where she served until 2006.

In 2006 she was appointed to Head the Department of Civil Registration. Upon appointment she embarked on processes to address the Departments capacity gaps in the areas of personnel, officeaccommodation and equipment. The Department now has reasonable number of personnel, offices and equipment to support efficient discharge of its mandate.

One of the current challenges facing the Department is the low coverage rate of Births and Deaths. She recognized that incomplete Vital Registration data cannot adequately inform decision making by various stakeholders. She has thus embarked on a campaign to seek participation and support from users of the Departments data to increase coverage rates.

During her 29 years in service, she has attended the following courses:

INDUCTION FOR ADMINISTRATION OFFICERS	K.I.A(Kenya)	1 month
SPEECH WRITING & PUBLIC SPEAKING	K.I.A(Kenya)	1 month
DISTRICT FOCUS FOR RURAL DEVELOPMENT	K.I.A (Kenya)	1 month
EFFECTIVE MANAGEMENT COMMUNICATION	K.I.A (Kenya)	1 month
SNR ADMINISTRATION OFFICERS PROGRAMME	INDIA, THAILAND & BRITAIN	6 WEEKS
KENYA IN INTERNATIONAL RELATIONS	U.O.N	2 WEEKS
INTER-PERSONAL SKILLS FOR SENIOR WOMEN MANAGERS	K.I.A (Kenya)	1 WEEK
COMPUTER APPLICATIONS	K.C.C.T	1 MONTH
ACHIEVING OUTSTANDING PERFORMANCE	SOUTH AFRICA	1 WEEK



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SPECIAL ASSISTANT FOR GLOBAL STATISTICS NATIONAL CENTER FOR HEALTH STATISTICS USA

Sam Notzon is Director of the International Statistics Program at the U.S. National Center for Health Statistics, CDC. He holds M.S. degrees in demography and economics from the University of Wisconsin (1973), and a Ph.D. in Population Dynamics from Johns Hopkins University (1989). He has worked in the area of international health statistics for more than 25 years, dealing with both developed and developing countries as well as multi-national organizations. He served as part of the Health Committee of the Gore-Chernomyrdin Commission, a US-Russia group dedicated to promoting collaboration between government scientists of the two countries. He is currently a member of the Statistical Advisory Commission of the Pan American Health Organization, WHO. He has also participated in several international collaborations sponsored by NCHS, on topics such as infant mortality, health data for the elderly, injury morbidity and mortality, and the use of automation in mortality data. His main area of interest is in international comparisons of health data, and in recent years he has focused on the U.S.-Mexico border, the Russian Federation, and Central and Eastern Europe.

PETER KIM STREATFIELD



HEAD, MATLAB HEALTH AND DEMOGRAPHIC SURVEILLANCE ICDDR, B, BANGLADESH

P.K. Streatfield, MSc (Physiol. Melb), MSc (Med. Demog. LSHTM), PhD (Demog, ANU), has worked in health and population research and training in developing countries for three decades, including 21 years living in Asia. For the past ten years he has managed the longest running and largest health and demographic surveillance system (ICDDR,B's Matlab HDSS) in the developing world, focusing initially on infectious diseases, but recently expanding into chronic diseases associated with ageing, particularly as they affect economic productivity in adult life. He is currently head of the ICDDR, B Population Programme as well as head of the Matlab HDSS.

He has been a member of the Technical Task Forces of all five Bangladesh DHS surveys, the national maternal mortality surveys (BMMS) 2001 and 2010, and the national Urban Health Survey 2006. In this capacity he combines a long interest in comparative sources of data (survey and surveillance) for generating evidence based health and population policy

He has been responsible for annual evaluations of performance indicators of the first Bangladesh SWAp – the health and population sector programme (HPSP, 1998-2003). He has directly conducted research in areas of family planning and other reproductive health programs, including maternal health, STD management, and sexual behaviour as HIV risk factors, nutrition and its integration into the national health programme, ageing and the health problems of the elderly, along with epidemiological studies on a diverse range of risk factors and outcomes, such as arsenic exposure. More recently, he has become involved in non-communicable diseases, their risk factors, and how to incorporate them in DSS systems. He is currently modifying the Matlab HDSS to contribute more effectively to long-term research on climate change and health.

Before coming to Bangladesh, he was Coordinator of the Ford Foundation supported Child Survival Project, Division of Demography & Sociology, Australian National University from 1985-1991. This was preceded by two years as UNFPA Country Advisor (Indonesia) at Gadjah Mada University, Yogyakarta, Indonesia. Before joining ICDDR,B he was Country Representative of the Population Council in Bangladesh for six years.

He has directly and indirectly worked on research studies with postgraduate students from over 30 countries while teaching several hundred Masters and PhD students at the ANU, supervising some 50 thesis students. He has been a Board member of the In-Depth Network of global health and demographic surveillance sites across Africa and Asia, and has participated in numerous technical groups of that network, including adult health and ageing.

PARALLEL SESSION 1.5:

CHOOSING AND USING STANDARDS FOR INTEROPERABLE INFORMATION SYSTEMS



HEALTH INFORMATICS STANDARDS KNOWLEDGE MANAGEMENT

ANDREW GRANT

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SUMMARY

The continuing evolving nature of Health Information Standards means that there is a real need and opportunity for communication between different categories of health information system user, between developing and developed countries and between users and standards developers. The concept of the Standards Knowledge Management Tool (SKMT) has grown out of the work entitled Health Informatics Profiling framework (ISO TR 17119). A Web portal has been put into use in 2009 under the auspices of the health information standards Joint Initiative for Global Standardisation to provide useful metadata about existing and developing standards and to enable a common glossary. The next aims are to provide methods of accessing this knowledge so that users can become rapidly aware of groups of health information standards that might apply to their particular use context. In addition ways of feedback to standards developers are under consideration.

INTRODUCTION

With increasing numbers and maturity of standards in health informatics it is essential for health informatics standards developers and also users to rapidly identify and retrieve existing health information standards content relevant to their particular need. Different categories of user may have different experience of standards and have different short and longer term needs; the requirement is to construct a knowledge management approach that takes into account these different needs.

Different approaches to classifying standards have been proposed. A pragmatic approach described in Canada in 2002 proposed 4 major groups: organisation and people (the stakeholders); process; information; and technology. A standards document can be assigned to more than one category. Some examples are given in table 1.

The Health Informatics Profiling Framework proposed in ISO TR 17119 in 2004 was designed to categorise health information artefacts within the domain of health informatics standards. It is based on a two-dimensional classification matrix, three levels vertically (specificity) of conceptual, logical and physical, and 6 horizontal columns of who, what, why, where, when and how, thus closely resembling the Zachman framework. Some examples of the application of this framework is given in table 2. The elegance of this approach nevertheless is somewhat frustrated by the need to become familiar with the classification which is not always immediately intuitive.

TABLE 1: EXAMPLES OF HEALTH INFORMATION STANDARDS CLASSIFICATION USING THE ACHI FRAMEWORK

ORGANIZATION AND PEOPLE STANDARDS Legislation Organization policies Program and service standards Resource standards	PROCESS STANDARDS Organisation procedures Business processes
INFORMATION STANDARDS Data structure Data content Data messaging Information and data management	TECHNOLOGY STANDARDS Application Integration Network Security Technology management

TABLE 2: EXAMPLES OF THE APPLICATION OF THE HIPF FRAMEWORK

CONCEPTUAL - WHO	CONCEPTUAL - WHAT
Healthcare organisation	Vocabularies and terminology
structures and structure models;	definitions (international and
Classifications of healthcare	jurisdictional);
organisations (e.g. government,	Data models, conceptual and
business, charitable,	associative (e.g. models con-
religious);	taining billing and appointment
Healthcare personnel typing	scheduling entities);
and classification models;	Models of factors affecting
Workflow models;	global health;
CONCEPTUAL - WHERE Climate models; Facility requirements (infrastructure)	CONCEPTUAL - HOW Guidelines for health information management; General and context dependent processes.

The coming together in 2008 of the Joint Initiative for Global Standardisation with representation from ISO 215, CEN 251, HL7, IHTSDO, CDISC was an important stimulus to propose and implement a web portal of core information about all existing health information standards called the Standards Knowledge Management Tool, SKMT. It also drew from work in ISO 215 defining the criteria for a health informatics glossary and its maintenance. The SKMT is designed as an internationally publically accessible web portal that informs users on all the existing and developing Health Informatics standards from ISO 215 and also CEN 251. It is also a source of health informatics terms and definitions recorded in the different standards documents, not only ISO 215 and CEN but also from CDISC and HL7. These terms are continuously reviewed to allocate the preferred definition to a given term and to show how different definitions may apply in different contexts, so enabling a single international vocabulary. The SKMT is publically available and can be consulted on www.cred.ca/skmt_glossary. A screen shot example is provided in figure 1.

FIGURE 1: SCREEN SHOT EXAMPLE FROM THE SKMT, STANDARDS KNOWLEDGE MANAGEMENT TOOL.

Joint Initiative for Global Health Informatics Docu Standards Knowledge Managemen	I Standards Harmonization ment Registry and Glossary at Tool
Log Out Search	Search Details
Search by Documents Search by Terms Go Search by:	safety (Candidate) [Add Watch] [Print] Language: English Definitions (Click on a definition to see the details. A blue background means a definition is Preferred.)
 Expression O Words User Profile Edit Profile Edit Watch 	Freedom from unacceptable risk of harm (Candidate) Version: 1 - 2009/04/08 Source: ISO/IEC Guide 51:1999 Context: None Image: Usage Comment:
	Definition is linked to Document Part(s): » Classification of safety risks from health software » Measures for ensuring patient safety of health software » Classification of safety risks from health informatics products
[♦ <u>Relationships</u> No Relationships

It should be noted in this screenshot that there is a close relationship between glossary, i.e. the terms which are given definitions in these documents and the documents. It is possible to move between documents and terms and between terms and documents. The term 'safety' and its definition is found in three standards documents. It is possible to click 'add watch' and you will be informed by email if a term definition is updated. When the tool became available it became possible to evaluate the situation where the same term has multiple definition may change if the context of the use of the term changes; the tool allows to add a context description with the definition. There is also the opportunity to signal the preferred definition and an ISO 215 group will monitor this.

METHODS AND DISCUSSION

A) EXPLOITATION OF THE SKMT

The documents referenced in the SKMT, with title and scope description, also are referenced to the standards development organisation and working group. This should help working groups to review their work, and also means that the tool can be used by a standards developer to locate previously published as well

as currently being developed standards which should create a more harmonious development environment. The developer is also made aware that a given term definition might already exist; locating it and its context may be influential in deciding how to use the term in the context of a particular standard development. In its current state the SKMT is already an importance reference for many types of user interested in developing an information system, in developed or developing world contexts as the principles expressed can have wide influence.

B) EXTENDING THE USABILITY OF THE SKMT

The challenges of knowledge management to support effective development and use of health informatics standards means that people, developers and users of different skills and backgrounds need to communicate so as to influence proper implementation of health information systems and furthermore to learn from this process.

Two initiatives are particularly being pursued i) the enabling of a library of use cases; ii) influencing feedback and context awareness to standards developers.

I) LIBRARY OF USE CASES

The use case is a pragmatic notion favoured by many system developers that can illustrate a process in an information system thus linking work flow, user roles and data and regulator dependencies. A single use case can call on different standards from different perspectives, for example terminologies, or data security, and illustrate the particular contribution of a standard to a particular situation. The current initiatives are therefore defining criteria for presenting such use cases. These criteria include that the use case description should be understandable by a broad range of users; that its description should be accompanied by a straightforward component analysis and how standards might relate to a given component. These components could be used to enable display of appropriate extracts of information about these standards from the SKMT. The SKMT should therefore incorporate a well indexed library of use cases and their components emphasising visual display and where possible graphical representations that can be used by implementing groups as explanatory material to their colleagues.

Use cases also will enable asking questions that should add value to a given implementation system. Should the SKMT enable links from use cases to other information that affect data management or best use of information systems, including even educational models? This is an exciting and in itself challenging opportunity influencing through example and inter-connection of interested parties how data quality might be encouraged, how data might be increasingly used in practice assessment and indeed how professional support can be linked to information system deployment. An emerging objective therefore for the SKMT is not only to support the relation of standards to standards implementation but also to support relationships between informatics implementers with other expertise in information management such as in disease surveillance and best practice encouragement, through understanding how these latter goals might tie into a particular component of a use case.

II) LEARNING AND FEEDBACK FOR STANDARDS DEVELOPERS

The proposed SKMT use case library and linking of standards to use cases opens up the potential for persons who access and take advantage of the use case based knowledge, to provide feedback of their experience about the use case and about components of the use case. This should improve the SKMT but also it will enable a catalogue of this experience to be provided back to the work group responsible for a given standard.

At present a usual standards document whilst detailing the different aspects of application possibilities do not give enough information about how the standard could be most useful in practice including in relation to closely related standards. It is intended therefore to involve the standards development organisation working groups in review of the proposed use cases so that their expertise can be brought to advantage in use case description in turn paving the way for the same working groups to receive feedback from actual use of the SKMT use cases in different worldwide settings.

CONCLUSION

Standards knowledge management is particularly exciting in enabling a new dialogue between users/system implementers and standards developers, sharpening understanding of the relevance of standards and their applicability on a worldwide scale. One barrier yet to be overcome is the access to the detail of standards and how this, for good reasons, requires a financial cost that in many cases might be an impediment to good use of the standard. The SKMT should encourage better choice of the most important standards for a given situation. It could also, if standards detail became available through the tool, motivate and monitor use of the standard. As the importance of standards is increasingly acknowledged, then the role of the standards development organisations is endorsed with perhaps adjustment of their business models to be less dependent on an item by item based revenue, perhaps adjusting to revenue through different agreements knowing how different standards are likely to apply to particular health information system implementations.

A FRAMEWORK FOR MONITORING SYSTEM DEVELOPMENT

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I. INTRODUCTION

In low-income countries, a strategy that balances development of systems for patient-care and international reporting can provide a path to timely population-based monitoring. Since both types of systems often pre-exist in a country, such a strategy would be cost-effective if effective data exchange can be implemented via a mechanism to exchange summary data with standard meaning in a standard format.

Results-based Monitoring and Evaluation, which requires documented performance measures, is driving enhancements such as target-setting and reporting of facility-level project and financial data. This presents an opportunity to develop a global monitoring infrastructure to enable seamless flow of data between the facility, subnational, national, and international levels.

A shift towards programme reporting in addition to development of patient-care systems is consistent with public health history. Some have suggested that public health programme management can have more impact on health than direct-patient care.¹ Indeed, four of the top ten Global Fund indicators do not come from a clinical record.

Top 10 Indicators for Routine GFATM Reporting

	1	HIV	Number of adults and children with advanced HIV infection currently receiving antiretroviral therapy
	2	ТВ	Number of (a) new smear-positive TB patients detected, (b) new smear-positive TB patients who were successfully treated and (c) laboratory-confirmed MDR-TB patients enrolled in second-line anti-TB treatment
Ē	3	Malaria	Number of (a) insecticide-treated nets or re-treatment kits distributed to people and (b) households (or structures or walls) in designated target areas sprayed by indeer recidual creating in the part 12 months
	4	Malaria F	our indicators are not from medical record.
			nauonai policy (specify artemisinin-oased combination merapy versus other therapy)
	5	HIV	Number of women and men aged 15–49 years who received an HIV test in the last 12 months and who know their results $$
	6	HIV	Number of HIV-positive pregnant women who received antiretrovirals to reduce the risk of mother-to-child transmission
Ē	7	HIV	Number of condoms distributed
Ē	8	HIV, TB and malaria	Number of people benefiting from community-based programs: specify (a) care and support including orphan support, home-based management of malaria and directly observed therapy (DOT); (b) behavior change communication outreach activities including specific target groups; and (c) disease prevention for people most at risk (except behavior change communication)
	9	HIV/TB	Number of TB patients who had an HIV test result recorded in the TB register
Ē	10	Health systems strengthening for HIV, TB and malaria	Number of people trained for improved service delivery in HIV, TB and malaria (specify (a) health facility or (b) outside facility)

The ISO 21667 Health Indicators Conceptual Framework elaborates a broad view of health further in a framework for classifying indicator definitions, as seen below.

Dimensions	Sub-dimensions				
health status	well-being	health conditions	human function	deaths	
determinants of health	health behaviors	socioeconomic factors	social and community factors	environmental factors	genetic factors
health system performance	acceptability	accessibility	appropriateness	competence	
	continuity	effectiveness	efficiency	safety	
community and health system characteristics	resources	population	health system		

This paper suggests that a broad-based monitoring system framework drawing data from disparate systems and encompass all facets of health would be based on an infrastructure consisting of three parts:

- Indicator Vetting and Harmonization Processes
- Indicator Registries
- Individual and Summary Country Reporting Systems

The system is based on a system of interoperable computer applications using a common data exchange format for summary data, which can be seen in Figure 1 below.



FIGURE 1 - A FRAMEWORK FOR MONITORING SYSTEM DEVELOPMENT

The diagram show the use of Health Level Seven (HL7) ²and Statistical Data and Metadata Exchange - Health Domain (SDMX-HD)^{3,4} to exchange data. Logically similar to the use of transmission formats like HL7 to link hospital systems containing patient data, the SDMX-HD is used to link systems producing or consuming aggregate data. A format for sharing aggregate data makes data available in low-connectivity environments, facilitating development of monitoring infrastructure.

II. BACKGROUND

Monitoring systems in low-resource countries have historically depended on tools like spreadsheets, vertical systems, and geographic mapping applications to store and manage data. A need for more robust data repositories emerged to support Monitoring and Evaluation (M&E) analyses as disaggregation, indicator management, and other weaknesses in design and scalability of applications became apparent.

In the absence of a common means to standardize and exchange indicator definitions, a proliferation of guidelines documents from international organizations paralleled the proliferation of systems in countries to collect that information as shown below.



FIGURE 2 - GUIDELINES DOCUMENTS

Increasingly, countries complained of being burdened with international reporting requirements, often reporting the same information in different required formats to multiple recipients and diverting scarce expertise to this task.

III. OBJECTIVES

Central to the development of this framework are contributions from the informatics community in data standards. The Statistical Data and Metadata Exchange (SDMX) standard, an ISO standard for describing statistical data, in particular, has been useful. Other aspects include increasing maturity of organizational work processes, the UNAIDS-hosted Monitoring and Evaluation Reference Group (MERG) being a notable example, and development of a variety of monitoring applications like CRIS (UNAIDS), DHIS, Devinfo (UNICEF). The three components are described as follows:

A. INDICATOR VETTING AND HARMONIZATION PROCESSES

Global organizations typically develop separate guidelines for local programme management and reporting. As indicator definition shifts from being organization or program-specific to being reference group-based, development of universallyaccepted definitions will be encouraged. The UNAIDS MERG is a good example of inter-organizational indicator development.

B. INDICATOR REGISTRIES

Development of the WHO Indicator and Metadata Registry is an attempt to create a tool to facilitate harmonization of indicator definitions across organizations. Analysts in reference groups can create, manage, harmonize, and publish global indicator definitions, which can be downloaded directly into computer applications. Multi-organizational views of metadata provides support for duplicative indicator definitions while harmonization efforts proceed.

More information on this online tool is available at: http://apps. who.int/gho/indicatorregistry/App_Main/browse_indicators. aspx

Complete indicator specifications, i.e. concept and metadata, provide guidance on data collection methodology, metadata required, and disaggregation, giving clear direction to both analysts and system developers. Electronic indicator definitions help to promote standard data-collection methodology and international standards with documentation and structure built into indicator definitions.

The SDMX-HD is the health domain's implementation of the ISO SDMX standard for aggregate data exchange³. Adoption of a standard transmission format alone, however, is not sufficient to permit data exchange. If a process for insuring conformance between implementations is not in place, then the data will not be comparable despite a standard syntax. The IMR addresses the harmonization of semantic content while the SDMX-HD addresses the syntax or 'boxcar' for the information. SDMX Metadata Common Vocabulary takes this further by attempting to standardize both for common statistical concepts across domains.

C. INDIVIDUAL AND SUMMARY COUNTRY REPORTING SYSTEMS

An added benefit of implementing data interchange standards in applications has been to promote differentiation of software. A combination of clinical, monitoring, analytic and geographic mapping software which can exchange data can provide a cost-effective comprehensive solution for countries.
IV. DESCRIPTION

The three parts of the framework vary widely among countries. Reference implementations of applications supporting the SDMX-HD have implemented SDMX-HD. Developers of OpenMRS, OpenEHR, CRIS, and DHIS are actively involved in this work. This is relevant since there are often multiple systems in a country collecting data and producing indicators.

While tempting to have a single system to simplify implementation, one application may be unrealistic and undesirable for long-term flexibility. A standards-based approach enables countries to mix and match applications as appropriate for requirements, selecting systems from bilateral, multilateral and private sector sources without being locked-in to one vendor.

V. SUMMARY

Integration of clinical systems with HL7 messaging complements integration of M&E systems with the SDMX-HD. Use of the two standards permits horizontal integration of clinical systems and vertical interoperability in the M&E system, helping to break down 'silos' of data, providing a seamless flow of data from the facility to district, national, and international levels. An opportunity exists to strengthen monitoring systems in addition to the improvement of patient care with international reporting requirements for UNGASS, Global Fund, and PEPFAR driving demand for facility-level data. This does not preclude the development of national clinical data warehouses as a longer-term goal, when required.

The global monitoring system schematic includes multiple domains in addition to different implementation scenarios. These scenarios vary depending on country circumstances such as existence of clinical systems, administration, connectivity, the location of aggregation of individual data, and other factors.

The mix of aggregate and individual-data systems and their location in the country reporting system will vary. Development of a Monitoring Maturity Model (MMM), adding another dimension to the one below for example, would be useful to describe individual and summary data systems in countries.

• Level 1 – Non-electronic data

No use of IT to share information (examples: mail, telephone).

Level 2 - Machine-transportable data

Transmission of non-standardized information via basic IT; information within the document cannot be electronically manipulated (fax or PC–based exchange of scanned documents, pictures, or PDF files).

Level 3 - Machine-organizable data

Transmission of structured messages containing non-standardized data; requires interfaces that can translate incoming data from the sending organization's vocabulary to the receiving organization's vocabulary; usually results in imperfect translations because of vocabularies' incompatible levels of detail (examples: e-mail of free text, or PC-based exchange of files in incompatible/proprietary file formats, HL-7 messages).

Level 4 - Machine-interpretable data

Transmission of structured messages containing standardized and coded data; idealized state in which all systems exchange information using the same formats and vocabularies (examples: automated exchange of coded results from an external lab into a provider's EMR, automated exchange of a patient's "problem list").

Source: Walker et al. http://content.healthaffairs.org/cgi/content/full/hlthaff.w5.10/DC1

Being able to accomodate both types of systems, data can move seamlessly from the facility or from the district to the international level, establishing the processes upon which future systems can evolve.

The data exchange standards are the heart of the monitoring architecture. The data exchange formats enable legacy, vertical, and local systems to be integrated into 'one' national Monitoring and Evaluation system, which includes clinical, populationbased, geographic, financial or programmatic data.

Creating a process for distribution of global indicator definitions, implementing standard data exchange formats, and developing technical capacity will accelerate the development of a global monitoring system. Components of this architecture have been developed and implemented at WHO with the development of the SDMX-HD and IMR.

Indicator registries provide a link between developers of indicator definitions and the informatics staff responsible for implementing them in systems. By pursuing development of interoperable systems, the Public Health Informatics community has the opportunity to simultaneously de-verticalize reporting systems, build sustainable country monitoring infrastructure, and satisfy international reporting requirements.

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CHOOSING AND USING STANDARDS FOR INTEROPERABLE INFORMATION SYSTEMS: APPLICABLE STANDARDS AND CONVERGENCE

JENNIFER ZELMER, CEO, IHTSDO

INTRODUCTION

Safe and effective exchange of health information is important around the world. Patients and their care providers need to be able to share information about health conditions, health services, and much more. They also need to be able to correctly interpret and trust the information that they record, send, and receive. The safe and appropriate exchange of clinical information is important to ensure continuity of care for patients across time, when they see different providers, and when they move between care settings. In an increasingly inter-connected and complex world, public health authorities, insurers, and others in the health system also need to reliably and efficiently transmit, analyse, and make inferences from health and health care information.

Seemingly simple questions involve many different stakeholders in the health system and potentially a range of information systems. For example, suppose that a patient needs emergency care and their health care provider wants to be sure that it is safe to give them a particular medication. Ideally, the health care provider would have ready access to information (subject, of course, to appropriate privacy and confidentiality safeguards) about the patient's problem list, allergies, current medications, and test results, as well as to the latest information about the drug in question and potential contraindications. This information may need to come from patients and families, other care providers, pharmacies, and bibliographic databases, among other sources. Likewise, to identify how far a new disease outbreak has spread, who is most at risk, and who might benefit from preventative treatment requires putting together information from many different sources. In both examples, speed and accuracy in the compilation and exchange of information may be important.

Progress has been made, but many challenges remain. Standards are key to achieving interoperable health information systems. They promise a number of potential benefits including opportunities:

- to underpin meaningful communication between health care providers and patients;
- to enable functions and services that would not otherwise be possible;
- to improve reliability, safety, and appropriate interpretation, analysis, and re-use of health information;
- to speed implementation and reduce duplication of effort and risks;
- to pool scarce resources in collaborative development efforts; and
- to provide broader options for purchasers of ehealth systems and/or market advantage for suppliers.

The standards process also has the potential to provide broad engagement of stakeholders from around the world in open, transparent, and fair processes with clear governance arrangements.

This is a shared challenge on a global scale. To this end, the 58th World Health Assembly urged Member States to "to mobilize multisectoral collaboration for determining evidence-based eHealth standards and norms, to evaluate eHealth activities, and to share the knowledge of cost-effective models, thus ensuring quality, safety and ethical standards and respect for the principles of confidentiality of information, privacy, equity and equality" (World Health Assembly, 2005).

TYPES OF INTEROPERABILITY STANDARDS

Many different types of standards are used in ehealth systems today, with the aim of promoting interoperability at different levels (Information Standards Board for Health and Social Care, 2008). Some standards are specific to health sector needs; others have broader applicability. Examples include but are not limited to:

- Governance and organizational frameworks and standards for ehealth systems, information access and exchange, and related functions;
- Privacy, confidentiality, security, and access to information standards and protocols;
- Information architecture, modeling, and structure standards that provide a foundation for interoperability;

- Identification standards for patients, healthcare providers, care settings, and other aspects of the care process to facilitate appropriate access, interpretation, and use of information;
- Content standards, such as standardized clinical terminology, to ensure clear, consistent, and safe recording, interpretation, and use of health information across time, care providers, and sites of care through semantic interoperability;
- Information exchange standards to structure information transmitted between two or more applications, reducing the need for custom interfaces between systems; and
- Technical standards (e.g. for medical devices and networks) to enable safe and effective use in an ehealth context.

CHOOSING STANDARDS

For one-time information that will not be re-used and that only needs to be interpreted by its creator, standards are less important. (Although even in this case, using standards may speed system development and acceptance or have other benefits). However, much of the information needed for clinical care, public health, quality improvement, and health system management does not fall into this category. In these situations, standards can be key.

In some cases, multiple standards are available in a given domain (e.g. different versions of a particular standard or standards created by different developers). In addition, standards of a given type may also exist at multiple levels because different types of users have different needs. In considering which standards to choose for a given application, a variety of factors should be taken into account. Examples include:

- Fitness for purpose including interoperability needs since different standards are often designed to address different needs or have other characteristics that may make them a better or worse fit in a given context;
- Ease of implementation and expected resource implications both in the short and long term;
- Safety of use in the environment in which the standard and associated systems will be deployed;
- Breadth of adoption and standards conformance in a given domain, regionally and internationally, and/or in the context of the ehealth systems that are being considered to meet a particular need;

- Stable, effective, and open governance, maintenance, and quality mechanisms, features which are particularly important for standards that will be used in patients' health records or other information that is likely to be required over long periods of time; and
- Responsiveness and adaptability because our knowledge about health, health care, and health informatics is evolving so ehealth standards should have mechanisms to do the same in an open and appropriate way.

In addition, it may be important to consider the extent of harmonization with other standards. Often, one will wish to use more than one standard together. For instance, SNOMED CT, a broad-based standardized health terminology, has been used in more than fifty countries, from hospital systems in Sri Lanka and Argentina to electronic medical records in sub-Saharan Africa and the United States or public health tools in the United Kingdom and the Middle East. Many, perhaps most, of these applications also employ messaging, technical, or other complementary standards. Therefore, assessing current and planned efforts that aim to make it easier to use multiple standards together and/or to work towards standards convergence may also be important when selecting standards for ehealth systems and networks.

CONCLUSION

Standards-based solutions that enable the safe and effective use and exchange of health information are helpful in both resource-poor and resource-rich contexts. Selecting and implementing an appropriate and complementary mix of standards can enable interoperability of health information systems, as well as the resulting benefits for patients and families, health care providers, and health systems.

BEATRIZ DE FARIA LEAO



CHAIR STEERING COMMITTEE HL7, BRAZIL

Beatriz de Faria Leão has an MD (1977) and a PhD (1986). She has done a Post-Doctoral in Health Informatics at the Medical Informatics Department of Erasmus University, Rotterdam (1989-90). She has been into health informatics since 1982 and she is one of founders of the Brazilian Health Informatics Association. Beatriz allies solid academic background to public and private sector experience. As academic she worked as an Associate Professor of Health Informatics at Federal University of São Paulo (1998-2000) and as an Associate Professor of Computer Science at the Applied Informatics Department at the Informatics Institute in the Federal University of Rio Grande do Sul, Porto Alegre, Brazil (1996-1998). She worked in as a Consultant at the Brazilian MOH from 2000-2004 in the National Health Card Project. Currently she's an independent consultant in Health Informatics with focus on Health Architectures and Standards where she concentrates her work. Beatriz is Convener of WG8 -Business Requirements for the EHR of the Brazilian mirror Committee of ISO TC 215 -- Health Informatics; and Vice-Convener of WG8 - at ISO TC 215. She's also Chair of HL7 Brazil Steering Committee



ANDREW GRANT

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Andrew McGregor Grant received his MB ChB in Medicine in 1970 from Birmingham University UK, his MRCP, Member of Royal College of Physicians in London 1975, his D.Phil at Oxford University 1983 in Clinical Biochemistry and his FRCPC, Fellow of Royal College of Physicians of Canada in Medical Biochemistry in 1990. In 2004 he was elected as fellow of the American College of Medical Informatics. He is full Professor at the Université de Sherbrooke and director of CRED: Collaborative Research in Effective Diagnostics, which has several research projects in Intelligent Systems and clinical data. He was 2005-2009 leader of the Health Services Evaluation Research Thematic of the Clinical Research Centre at the Centre hospitalier universitaire de Sherbrooke, Quebec. He leads the first online courses in Health Informatics for health professionals and in Health Information Standards in Canada. 2004-2006 he was co-president of the Standards Steering Committee of Canada Infoway and now serves on the Canada Infoway Standards Technical Coordinating Committee. He is member of the Canadian delegation to ISO 215 in Health Informatics and leader of its Clinical Data Warehouse activity; he also is elected member of the Technical Committee of the International Health Terminology Standards Development Organisation IHTSDO. He was president of the Quebec Society of Biomedical and Health Informatics, SoQibs, 2002-2004 and currently serves as vice-president. He received the Canada Health Infoway - Partnerships peer award in 2006.

WILLIAM HAMMOND



DIRECTOR DCHI/DTMI

W. Ed Hammond is Director, Duke Center for Health Informatics. He is Professor, Department of Community and Family Medicine; Professor, Department of Biomedical Engineering; and Adjunct Professor in the Fugua School of Business at Duke University. He has served as President of the American Medical Informatics Association (AMIA), President of the American College of Medical Informatics, and as Chair of the Computer-based Patient Record Institute. He is currently serving his third term as the Chair of Health Level 7. He has just completed a term as Chair of the Joint Initiative Council (ISO, CEN, HL7, CDISC, IHTSDO, and GS1). He was Chair of the Data Standards Working Group of the Connecting for Health Public-Private Consortium. Dr. Hammond was a member of the IOM Committee on Patient Safety Data Standards. Dr. Hammond was awarded the Paul Ellwood Lifetime Achievement Award in 2003 and the ACMI Morris F. Collen Award of Excellence in November 2003.



PATRICK WHITAKER

TECHNICAL OFFICER WORLD HEALTH ORGANIZATION

Patrick Whitaker is a member of the World Health Organization (WHO) Healthcare Informatics Unit where he is involved with international standards activities as the WHO liaison to ISO TC 215. He also manages the WHO Indicator and Measurement Registry (IMR), a facility for defining, managing, harmonizing, and publishing international indicator definitions, and chairs the group supporting the SDMX-HD summary data standard.

Prior to arrival at WHO, Patrick developed the Country Response Information System (CRIS), a general-purpose monitoring system to support UNGASS HIV/AIDS reporting to UNAIDS. This system demonstrated streamlined electronic reporting at both subnational, national, and international levels, support for programmatic reporting and Monitoring and Evaluation (M&E), and other innovations based on close association with the UNAIDS Monitoring and Evaluation Reference Group (MERG) and U.S. Government PEPFAR.

Patrick worked for the U.S. Centers for Disease Control and Prevention for seventeen years, managing international surveys, epidemiologic studies and clinical trials in reproductive health and HIV/AIDS. During 1992-96, he was Chief of the Informatics Section at Projet RETRO-CI in Abidjan, Côte d'Ivoire with Drs. Kevin DeCock and Alan Greenberg.

Patrick attended the University of North Carolina, obtaining a Masters in Public Health from the School of Public Health in 1978, and the Georgia Institute of Technology, obtaining a Master of Science in Management of Technology from the DuPree School of Management in 2000.



JENNIFER ZELMER

CHIEF EXECUTIVE OFFICER INTERNATIONAL HEALTH TERMINOLOGY STANDARDS DEVELOPMENT ORGANIZATION (IHTSDO)

Jennifer Zelmer is CEO of the International Health Terminology Standards Development Organisation. Prior to joining IHTSDO, Jennifer led programs related to health information standards and analysis at the Canadian Institute for Health Information and worked with a variety of health, academic, and government organizations in Canada, Australia, Denmark, and India. Ms. Zelmer is an adjunct faculty member at the University of Victoria and has been a member of several health-related advisory committees and boards. She has a Bachelor's degree in Health Information Science and a PhD in Economics.

PLENARY SESSION 2:

STEPPING UP TO THE PLATE:

WHO DOES WHAT TO IMPROVE HEALTH INFORMATION FOR MONITORING HEALTH-RELATED GOALS?

Global Health Information Forum

ISSUES TO BE COVERED:

1) Results-based development: are we doing too little or too much to measure results?

Will we know if we achieve the MDGs?

- Are investments in health information systems sufficient and efficient?
- What's required to move beyond the "garbage in: garbage out" syndrome?
- How quickly can change in health be measured?
- How accurately can investments in health services be associated with changes in health?

2) Meeting information needs of diverse programs and stakeholders through a harmonized and aligned health information system: panacea or pipedream?

- Are global funds and global disease programs related to the MDGs a friend or foe of health information systems?
- Progress towards one M+E system for HIV/AIDS
- Women's lives: who's counting?

3) Reducing transactions costs of disease-specific information systems

- What are the common platforms that serve multiple disease needs and how can they be supported more effectively?
- How facility and administrative unit (district/province) information systems become more dynamic, flexible and accommodating of specific disease information needs?
- Towards more strategic investments in health information systems and donor harmonization



TIES BOERMA

DIRECTOR, DEPARTMENT OF HEALTH STATISTICS AND INFORMATICS WORLD HEALTH ORGANIZATION

Director of the Department of Health Statistics and Informatics at the Information, Evidence & Research Cluster WHO. Obtained degrees in medicine (MD) and demography (PhD) and has over 25 years of experience working in public health and research programmes in developing countries, including 10 years based at district level in Africa. Has worked for different UN organizations, bilateral donors, national governments and research institutions and has published extensively on AIDS, maternal and child health in epidemiological, demographic, and public health journals.



TIMOTHY EVANS

ASSISTANT DIRECTOR GENERAL INFORMATION, EVIDENCE AND RESEARCH WORLD HEALTH ORGANIZATION

Dr Tim Evans, of Canada, is currently the Assistant Director-General for Information, Evidence and Research. From 2003 to 2007, Dr Evans served as the Assistant Director-General for Evidence and Information for Policy. He has a Bachelor of Social Sciences from the University of Ottawa and a D.Phil in Agricultural Economics from the University of Oxford, as well as a Doctor of Medicine from McMaster University in Canada.

Dr Evans trained in internal medicine at the Brigham and Women's Hospital at Harvard University. He was an assistant professor of international health economics at the Harvard School of Public Health. From 1997-2003, Dr Evans was Director of Health Equity at the Rockefeller Foundation.



MARK LANDRY

SENIOR INFORMATICS SPECIALIST PEPFAR OFFICE OF THE GLOBAL AIDS COORDINATOR

Mr. Landry, MSc, serves as the senior informatics specialist with PEPFAR, and is part of the Strategic Information (SI) Division within the Office of the U.S. Global AIDS Coordinator (OGAC). One of his chief responsibilities is coordinating U.S. government (USG) efforts to strengthen health information systems (HIS) across all levels of host country governments and throughout the health system. Mr. Landry develops PEPFAR policies and guidance to aid USG agencies and implementing partners in support of HIS capacity building and achieving and monitoring HIV/AIDS prevention, care, and treatment goals. Mr. Landry coordinates with the Health Metrics Network, WHO, the World Bank, philanthropic foundations and other donors to leverage global resources and technical assistance more effectively while facilitating greater local coordination and implementation strategies championed by host governments. Going forward, PEPFAR will serve as a key component of the U.S. Government's Global Health Initiative, which will focus on health system strengthening (HSS), country ownership, sustainability, and shift towards building localized technical assistance capabilities to deliver institutional and individual HIS capacity building. Mr. Landry's technical and managerial areas of expertise include national and sub-national HIS assessment, strategic planning, and capacity building; adoption and use of systems standards and enterprise architecture; design, development, and implementation of electronic medical records and routine HIS; health data integration and use; building health geographic information systems (GIS) for evidence-based programmatic targeting, planning, management, service delivery, and quality of care decision support. He has provided HIS, eHealth, and HSS technical assistance to numerous countries in Africa, Asia, the Middle East, and to a lesser extent, the Latin America region.



DANIEL LOW-BEER

UNIT DIRECTOR, PERFORMANCE IMPACT AND EFFECTIVENESS THE GLOBAL FUND TO FIGHT AIDS, TB AND MALARIA

Dr. Daniel Low-Beer is Director of Performance and Effectiveness at the Global Fund, where he has worked since 2004, leading performance based funding, aid effectiveness and results. He worked in WHO at the Global Program on AIDS in the early 1990s in Global AIDS surveillance and evaluation, and providing the scientific evidence behind early HIV prevention successes in Uganda and Thailand, behaviour and communication changes, the first demographic impact of AIDS, and led the first Global Burden of HIV study. He subsequently worked in strategy consulting, as Director of the health and population evaluation unit at Cambridge University, and in HIV prevention in Southern Africa. He has worked with Ministries of Health in Africa and Asia, as well with USAID, DFID, Johns Hopkins Centre for Health Communication, NGOs in South Africa, and the OECD executive committee on aid effectiveness.



SANIA NISHTAR

PRESIDENT & CEO HEARTFILE ORGANIZATION

Sania Nishtar is the founder and president of the NGO think tank, Heartfile, which today is the most powerful health policy voice in Pakistan and is recognized as a model for replication in other developing countries. Her areas of interests are health systems reform, broader issues of governance and public-private relationships, reorientation of priorities in health and global health.

In Pakistan her work in the health sector has inspired new initiatives and has shaped policies on health reform and non-communicable diseases. She is also the founder of Pakistan's Health Policy Forum and provides support to many agencies in an advisory role. Within Pakistan, she is also a voice to catalyze change at the broader governance level as a weekly op-columnist in Pakistan's largest English newspaper. She additionally sits on many governing boards and is a visiting faculty to many educational institutions.

Internationally, Sania Nishtar is a member of many Expert Working Groups and Task Forces of the World Health Organization and is currently a member of the board of the International Union for Health Promotion and the Alliance for Health Policy and Systems Research. She is also a member of the World Economic Forum's Global Agenda Council, the Clinton Global Initiative, the Ministerial Leadership Initiative for Global Health and many other international initiatives. She has formerly been on several international Boards, and has chaired several global campaigns and programs. She has also been an advisor to WHO on numerous occasions, has published over 100 journal articles and is the author of 4 books. Her book on Health Reform entitled 'Choked Pipes' will be released by Oxford University Press in February 2010.

She speaks to audiences around the world and has been extensively published in and quoted in the media. Sania Nishtar is the recipient of Pakistan's Sitara-e-Imtiaz, the European Societies Population Science Award and 16 gold medals. She was named as the International Health Professional of the Year 2007 by the International Biographical Centre, Cambridge

Sania Nishtar holds a Fellowship of the Royal College of Physicians of London and a Ph.D. A detailed profile can be accessed at http://www.sanianishtar.info



FRANK NYONATOR

DIRECTOR, POLICY, PLANNING MONITORING AND EVALUATION DIVISION GHANA HEALTH SERVICE

Dr. Frank Kwadjo Nyonator (MD. MPH. FGCPS) is a public health physician – specialized as a health systems expert - with management and organisational development experience including in-service training, capacity building and project management skills.

He has extensive experience, with leadership and teamwork, in planning, formulating and translating policies on health services delivery at international, national, regional and district levels. He provides advice to Governments, Ministries of Health and Development Partners in Health Sector Reforms in Africa at both policy and implementation levels. He is currently the Director for Policy, Planning Monitoring and Evaluation of the Ghana Health Service with the responsibility for planning, budgeting, monitoring and evaluation of country specific programs including that of monitoring the Global Health Initiatives – GAVI HSS and Ghana Global Fund for HIV/AIDS programming at the district, region, and national level.

Dr. Nyonator was a lead Member of the Health Service Technical Team in the development of the Ghana Macro-Economics and Health Initiative (GMHI) to review and increase investment for health within the Ghana Poverty Reduction Strategy (GPRS). Was a member of the National Task Force for Health Financing Reforms in Ghana

He, currently, provides leadership for the monitoring and evaluation countrywide implementation of Primary Health Care component of district health systems strengthening - the Community-based Health Planning and Services (CHPS) in Ghana – an innovative and efficient way of bridging the access gap in health service delivery and the efficient use of available human resource for health that has attracted international attention.

He is a Lecturer at the Faculty of Public Health in the Ghana Post Graduate College of Physicians and Surgeons. He has served as a faculty member of the World Bank's Flagship Course held in Washington from October 27-30. He has been a member of the Technical Steering Committee of the Child and Adolescent Health (CAH) Department, WHO HQ Geneva, as the Health Systems Expert. He had also served on two Independent Review Committees (IRC) of GAVI Alliance – a) New Proposals Independent Review Committee and b) Health Systems Independent Review Committee.

He served as the Vice Chair of the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) Joint Coordinating Board (JCB) from June 2006 to June 2007.

He was Health Systems Specialist in the WHO Country Office, Abuja, Nigeria from June 2008 to June 2009 to support the Federal Ministry of Health to develop their current Strategic Health Plan with support from IHP+.

Dr Frank Nyonator is a Founding Member of Health Systems Action Network (HSAN).

Prince Mahidol Award Conference 2010

PARALLEL SESSION 2.1:

TRACKING COUNTRY HEALTH SYSTEMS PERFORMANCE



PARP SION

TÉA COLLINS, MD, MPH, DrPH, MPA SENIOR HEALTH SYSTEMS SPECIALIST/DIRECTOR, RESEARCH AND PROGRAMMES GLOBAL FORUM FOR HEALTH RESEARCH GENEVA, SWITZERLAND

THE PUBLIC'S ROLE IN MEASURING HEALTH SYSTEMS PERFORMANCE: AN EXAMPLE OF GEORGIA

INTRODUCTION

The importance of measuring health systems performance cannot be overstated. There are many frameworks that attempt to perform that task. The most well-known is the WHO framework for assessing health systems performance, which recognizes that the "intrinsic goals" of any health system are improved *health status, responsiveness* to public expectations and *financial risk protection.* Following this framework, this paper starts with a snapshot of research in Georgia, which provides important insights into people's perceptions of the health systems' performance on all three goals. The second part of the paper calls for a "people centered' comprehensive framework to measure health systems performance.

DISPLACED PEOPLE'S PERCEPTIONS OF THE HEALTH SYSTEM IN GEORGIA.

After the break-up of the Soviet Union, internal wars in Georgia had displaced a large number of families, causing a surge in migration to the capital of Tbilisi. The health needs of these families were large. However, the government neglected to assess these needs. In the first years of displacement the people were given humanitarian assistance and healthcare, but after a few years it became a political liability to have displaced people in the capital, and the information about the displaced simply started to disappear. The poorly functioning health information system contributed to this situation. The system did not register the internally displaced people (IDP) as a separate group with special health needs. The result was that many households were unable to obtain the care they needed.

A study conducted by the author (Collins 2006) compared the perceptions of Georgian internally displaced women (sole healthcare decision-makers in families) and policy-makers toward the health system performance as a result of health reform, and concluded that there was a wide disparity of perception. Focus group interviews as well as in-depth faceto-face interviews with key informants were conducted in Tbilisi.

The study revealed that the consumers' perceptions of the health system were significantly different from that of policy makers. From the consumer's perspective, the health system was failing all three "intrinsic goals:" most internally displaced women (IDW) respondents felt that their health status was poor and that they needed medical attention. However, they were not able to afford the care they needed, and the quality of services was poor. These findings were not surprising, since the negative consequences of war on one's health are well documented and may occur several years after a conflict ends (Ghobarah, Huth, Russet 2001).

"We now have to make the choice between having an operation or feeding our family. For most, the choice is clear, we do not go to hospital." (IDW)

"At least during the Soviet times the care was free for everybody. Now we need to pay for the same quality services." (IDW)

Even though healthcare providers for IDPs repeatedly mentioned that the health status of the displaced was deteriorating, the trend data wasn't included in reports to the government. The Center for Medical Statistics and Disease Control (CMSDC) collected the population's morbidity and mortality statistics directly from the medical facilities in Tbilisi and all regions of Georgia, but in the annual reports that were forwarded to the Ministry of Health, the health data of IDPs were incorporated into the population statistics of respective regions and were not reported separately. This made it impossible to have comparative statistics of IDP health indicators vs. the general population. The Center's administrators explained that IDPs seek medical care from different institutions, which do not record their status separately, and therefore IDP data could not be disaggregated. Further, the Center had no special directives from the Ministry of Health to collect IDP health data separately.

The author was able to obtain some data on psychoneurological disorders directly from the Psycho-neurological Dispensary, which served only IDPs. The official data revealed that psycho-neurological disorders among IDPs were not uncommon. Among 60 IDP patients registered in the Dispensary in Tbilisi in 2003, 58 were in the 20-59 age group, and 21 were women. These data compared unfavorably to the 2002 statistics in the whole of Tbilisi, where only 33.2 patients (general population) were registered in 2002 (CMSDC 2002)

However, the government officials did not share the concerns of IDWs. Even though they recognized the problems with the current system, they were quick to respond that these problems would not exist in the "new" system, that the government had already provided "enough help" to the displaced and that after all, "the rest of the population was not doing any better." Overall, the government believed that through the development of a competitive environment in health care, the quality and efficiency of that environment would be improved.

The fact that the government did not collect health statistics on IDP health needs indicated that this group was not considered a vulnerable category and hence, did not deserve priority targeting. This decision had devastating implications for IDW health.

A NEED FOR A COMPREHENSIVE FRAMEWORK TO EVALUATE HEALTH SYSTEMS PERFORMANCE

The Georgian situation is complex and should be viewed in the context of the complicated socio-economic environment in the country. However, the health system still has a significant role to play in securing health for the whole population.

The value of measuring health systems performance is not in doubt. The trend toward measuring performance has been strengthened by the increasing use of performance measures in funding and service delivery at all levels of the health sector.

However, there is no agreement as to the framework that should be used. Several frameworks for measuring health systems performance have been proposed. Most of them have tried to address health system goals related to health status, health inequalities, equitable financing, quality, consumer satisfaction, allocative and technical efficiency, coverage, cost containment, political acceptability and financial sustainability. In contrast, the WHO framework for evaluating health systems performance is based on a single composite measure of performance. The methodology, proposed in WHO's World Health Report 2000, ranked 191 countries' health systems according to an overall index of performance.

WHO's index was composed of three composite indicators (intrinsic goals of the system): health improvement (overall level of population health and health inequalities); health system responsiveness to the consumer (a combination of patient satisfaction and how well the system responds to patients' needs); and fairness of financial contribution (distribution of the health system's financial burden within the population). In addition, there were two types of "components for assessment" of goal achievement, average level and distribution, which were applied to the first two goals (health improvement and responsiveness). The result was five components of health system performance

This WHO framework for evaluating health systems performance has been a subject of extensive debate and criticism on the part of public health experts. Some of them (e.g. Navarro, 2001) questioned the importance of creating one single indicator (performance index) to measure performance. The argument was that, after all, there is no single indicator for ranking countries by economic performance. Rather, the annual UN economic reports use specific indicators to measure different components of economic efficiency, such as unemployment, economic growth per capita, rate of productivity growth and so on.

The advantage of composite indices and rankings is that they give policy-makers important tools to make decisions in a relatively short period of time. Policy-makers can use composite indices as a snapshot of system performance before compiling all the necessary data to determine where change is desirable or feasible. However, if composite indicators are not carefully designed, they may be misleading and contribute to poor policy making and public health programming. Of particular difficulty is the choice of weights attached to the component measures, since there is little agreement across the globe on core values in health. Another challenge is the difficulty of translating the overall *population's health status* indicators into specific policies and programs. First, the aggregate measures do not provide a clear picture of the health needs of disadvantaged population groups. A fundamental challenge for performance measurement becomes the difficulty of designing health information systems that serve the needs of diverse populations (Smith et al. 2008). Second, even though the contribution of the health system is easily captured in terms of clinical outcomes to patients, it is difficult or impossible to

estimate the contribution of the health system to populations' health, which is heavily influenced by factors outside the health system – so-called social determinants of health.

Measuring health systems responsiveness is challenging as well, since it requires information from patients as well as the general public. *Financial protection* from catastrophic expenditure related to ill health is an issue particularly in lowincome countries where health coverage is not universal. The challenge is also to estimate the long-term implications for household wealth and savings (Smith et al. 2008). Because of these difficulties, it is apparent that the first step in any performance measurement is to develop a comprehensive conceptual framework within which performance measures can be developed. Ideally, along with guantitative measures, the conceptual framework should also incorporate the gualitative dimension of the public's perception of the health system performance, since the public's perceptions of healthcare services and their ability to make informed decisions greatly influence the use of the healthcare system.

The fact that experts' and consumers' perceptions of health systems often do not coincide is supported by evidence and indicates the need for public participation in health systems performance assessment. In line with the Georgian study, a study by Blendon, Kim and Benson (2001) compared the results of the WHO rankings for seventeen industrialized countries in terms of the healthcare delivery system's responsiveness, to perceptions of their citizens. The results showed little relationship between WHO rankings and the satisfaction of the citizens who experience these health systems. The health systems of some top WHO performers were rated poorly by their citizens, including the elderly and those of low income. Conversely the two countries rated most highly by the public rank at the bottom of the WHO ratings.

CONCLUSION

It is clear that the failure of health information systems to identify and document the health needs of vulnerable populations may result in policy-makers being unable to identify and target the most needy, and ultimately save more lives and improve the efficiency of health programs.

Citizens' perceptions of health systems is as valuable as the opinions of experts, since the public is the ultimate beneficiary of the health system. The performance measurement framework should consider the citizen's perspective to provide unbiased estimates.

Although important, the value of composite population health measures is limited. When the data on every population group is not available through existing health information systems, some simple research tools, such as focus group discussions and rapid appraisals, can be used to derive information for the performance measurement framework.

Research-based evidence often plays a very minor role in policy processes. As a consequence, policy-making is often flawed. Health information systems are the most underfunded and under-researched area of health systems research. More research is needed on how to design health information systems that can be responsive to diverse population needs.

The crucial need for effective epidemiological data collection, analysis, and distribution cannot be overemphasized. These are essential to understanding risk factors to health and the measures to control them, for those at the policy, provider, and community levels. Relevant data, widely available, would improve the ability of policy-makers, health providers, and the general public to address health issues and etiological risk factors for disease. On the basis of well-developed health information systems, the most cost-effective health programs can be designed to meet the people's needs.

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Prince Mahidol Award Conference 2010

SOUTH AFRICA: MONITORING HEALTH SYSTEM PERFORMANCE AT SUBNATIONAL LEVEL

CANDY DAY

South Africa is a unique and highly diverse country, described sometimes as 'the world in one country'. The country has 9 provinces divided into 52 districts, and 11 official languages. There is massive diversity in the geography, climate, ethnic groups, social values, socio-economic status, burden of disease, population density and health outcomes across these areas. In addition to this, the political history and vast inequities which persist, make it imperative that the health system is monitored not only at provincial and national levels, but also at district level or lower where possible. There has thus been a huge need to develop and strengthen information systems which are capable or producing timeous, reliable information and low levels of aggregation, within severe resource constraints.

The District Health Barometer (DHB) is a tool which has been developed to provide a regular snapshot of the overall performance of the public health sector across the provinces and health districts in South Africa, focusing on primary health care (PHC). It has contributed to understanding inequities in the health system, through the integration of detailed, disaggregated time series data from sources such as the District Health Information System (DHIS), National Treasury expenditure data, Electronic TB register (ETR.net), antenatal HIV seroprevalence surveys and Statistics South Africa surveys.

The DHB seeks to highlight inequities in health outcomes, health resource allocation and outputs as well as track the efficiency of health processes between provinces and between all districts in the country, with particular emphasis on rural and urban (metropolitan) districts. The report also functions as a tool to monitor progress towards strategic health goals such as the Millennium Development Goals (MDGs) and to support the improvement of provision of PHC and the improvement of the quality of routinely collected health data. The analysis of indicators between districts assists in identifying successes, gaps and potential corrective measures within the health system. The DHB also fulfils some of the roles of a Public Health Observatory, by making population and health indicators readily available, and engaging with a wide range of stakeholders.

TRACKING TRENDS IN INEQUITIES AT SUB-NATIONAL LEVEL

Inequity can be assessed in terms of several dimensions including geographic area, socio-economic status and individual characteristics such as race, gender or age. The latter are not available from routine aggregated data, and thus the deprivation index (DI), a composite measure of relative deprivation between areas, has been developed to facilitate comparison of health indicators according to socio-economic quintiles (SEQ), or need. The DI and SEQs have been calculated for a series of years, and also expanded to sub-district level in 2007.



Using 'Non-hospital PHC expenditure per capita' as an example, it can be seen that although there is an increase in the absolute difference between the highest and lowest expenditure by district, the relative difference is decreasing, and both the absolute and relative difference between the best and worst socio-economic quintiles are slowly decreasing, suggesting a gradual improvement in financing equity. (The absolute gap is the difference in indicator values for the disadvantaged group (SEQ 1) and the reference group (SEQ 5). The relative gap is the ratio or percentage difference between these values.)



On the other hand, when considering a key socio-economic determinant for health, the proportion of households with access to piped water, there has been remarkably little improvement in inequities between districts even though there has been an overall improvement at a national level.

The most striking feature of a simple line graph of household access to piped water at district level, grouped by province, is the wide disparities in some provinces such as Eastern Cape (EC) and KwaZulu-Natal (KZN), compared to Free State (FS) and Western Cape (WC) – which are concealed if one only monitors the national trend. When considering the distribution of household access to piped water at district level according to district type (using a box-andwhisker plot) the disparity between ISRDP (rural) areas and metros is dramatic, and there has been very little improvement over time.



THE POWER AND PITFALLS OF ROUTINE DATA

A thorough assessment of the usefulness and problems of routine or administrative data sources for health indicators is beyond the scope of this paper, therefore only a selection of key issues from our experience will be highlighted here.

Despite relatively low levels of financial and human resources, the DHIS has been rolled out across the country, and is currently the main source of regular information for planning and management of health services. Although discrepancies do occur, in general there is standardisation across the country of the definitions of data elements and data flow policies. One of the major advantages of the system is that it provides relatively simple access to a wide range of integrated health indicators, including all levels of the public health system, and even integrating selected key information from surveys and other primary data sources.

DATA VERIFICATION

There is inadequate monitoring of indicators throughout the system, from facility to national levels. This has resulted in some districts having indicator values that are clearly implausible.



Selected examples of removing outlier data at district level

There has been very little regular and comprehensive verification of the data quality from routine systems, however published papers evaluating selected aspects of DHIS have found significant discrepancies in the completeness and accuracy of data. It appears that the main source of inaccuracylies in the data collection tools at health facilities and the summary and transfer of these records into the software system.

DATA VALIDATION WITH EXTERNAL DATA SOURCES AND INFORMATION

Despite the multitude of data quality problems, for some indicators there has been good correlation with external data sources (for example HIV prevalence among antenatal clients) and consistency over time (for example PHC utilisation rate, which shows consistent seasonal variation and changes corresponding to known events such as health worker strikes).




DATA LIMITATIONS

Routine health information systems currently have virtually no patient-level clinical data.

LIMITED PRIVATE SECTOR DATA ARE CAPTURED IN THE SYSTEM.

Certain indicators are not amenable to this type of data collection. For example monitoring of the implementation and outcomes of the PMTCT programme involve numerators and denominators which may be collected over the time period of the pregnancy, at different health facilities, since initial antenatal care may take place at a different location to the delivery.

There are issues with disaggregated data for rare events such as maternal or perinatal deaths. Small data errors can dramatically affect indicator values, and at low levels of disaggregation indicator values do fluctuate widely, particularly for areas of low population density.

Looking at monthly data for an indicator like Perinatal Mortality Rate (PNMR) shows that the difference between districts is less than the range of variation in the data because perinatal deaths are relatively few at this level of disaggregation.



INTEGRATION OF DATA FOR MORE EXPLANATORY ANALYSIS

Although there are some national structures and initiatives involved with the co-ordination and harmonization of health information systems and data sources, it is widely acknowledged that overall integration and use of systems is inadequate, and many have substantial data quality problems. The DHB has worked with some of these data sources, developing coding to connect the DHIS with expenditure data and selected survey-based socio-economic determinants. There have been many challenges with this due to lack of standard coding for health facilities, geographic areas and a general lack of consistency or documentation. In addition the structure and content of the information changes each year, so the process of integration between data sources requires ongoing work.

Some important areas of data integration have been highly problematic, in particular the human resource information system, due to fundamental deficiencies in how the data are collected. It is clear that despite the need for interoperability between information systems for effective health systems management and assessment, some systems have not been responsive in putting the fundamental architectural components in place to facilitate integration of data.

Integration of data from other sectors is also vital for monitoring of multi-sectoral interventions, and further work is planned to develop and improve linkages between these sources.

SUMMARY

As part of HIS strengthening, South Africa undertook a national HIS assessment in March 2009, using the Health Metrics Network framework. These results are based on scoring by the participants present and each area covers a number of different data sources which may be of different adequacy making it difficult to generate an accurate result – however it does give an overall feel for perceptions of the adequacy of data sources. In general, surveys and StatsSA sources received higher ratings, while health and resource records were generally found to be problematic.

Data Source	Contents	Capacity & Practices	Dissemination	Integration and use	Total
Census	Highly adequate 100%	Highly adequate 75%	Adequate 71%	Adequate 56%	Highly adequate 75%
Vital statistics	Highly adequate 89%	Adequate 67%	Highly adequate 100%	Highly Adequate 83%	Highly adequate 85%
Population-based surveys	Adequate 57%	Highly Adequate 88%	Highly adequate 100%	Present but not adequate 33%	A dequate 70%
Health and disease records (incl. surveillance)	Adequate 56%	Adequate 59%	Present but not adequate 44%	Present but not adequate 28%	Present but not adequate 47%
Health service records	Not adequate at all 12%	Present but not adequate 41%	Highly adequate 78%	Adequate 50%	Present but not adequate 45%
Resource records	Adequate 63%	Present but not adequate 40%	Present but not adequate 33%	Present but not adequate 31%	Present but not adequate 42%
Total	Adequate 63%	Adequate 62%	Adequate 71%	Present but not Adequate 47%	Adequate 61%

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HEARTFILE'S FRAMEWORK FOR HEALTH SYSTEMS PERFORMANCE ASSESSMENT

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The recent increased attention to time-bound outcome-based targets embodied within the Millennium Development Goals has led to the realization that health systems constrains, which impede progress towards achieving these objectives, must be addressed.

As a result, most global health initiatives have recently been according higher priority to strengthening developing country health systems. In parallel, the need for monitoring performance and evaluating progress in countries, in line with the Paris Declaration on Aid Effectiveness is also being appreciated, especially in view of the unprecedented increase, in absolute terms, of official development assistance for health over the last two decades. However, as opposed to other domains of health information, health systems performance assessment has remained a grey area in information systems research in low-income countries, as opposed to the OECD countries, where substantial work has been done.

A number of normative frameworks have been created over the last decade. Most of them used composite indicators, as a result of the multidimensional nature of health systems performance assessment and the need for different measures, methods and instruments to capture each element of performance.

The World Health Organization's analytical framework, which formed the basis of country health systems performance ranking in the World Health Report 2000, used fixed weights to derive a composite score from five indicators, based on which 191 countries were ranked., The framework provoked international debate primarily as a result of country positions in the ranking and issues concerning the methodology adopted., The tool was meant for cross-country comparison and was not tailored for national and sub-national level performance assessment.

Composite scoring for overall rating and balanced score cards to summarize statistics for different domains of systems performance were also used for individual countries, and for assessment of a particular systems' attribute. The latter was applied to Demographic Health Surveys for developing coverage and co-coverage scores for preventive interventions in Mexico.

The recent demand for health system monitoring and evaluation comes from the emphasis on health systems within the UN system, the G8, the International Health Partnership Plus (IHP+), and the WHO-led Platform to Strengthen Monitoring and Analysis of Country Health Systems. IHP+ promotes support to national health strategies and plans—including strengthened information systems for monitoring and evaluation—as a means of increasing alignment around national priorities. The IHP+ and the WHO platforms focus on methodological approaches, which are needed to improve data availability and quality and sustainable ways of catalyzing health systems monitoring and building capacity within countries.

Heartfile, a policy think tank in Pakistan has developed an assessment framework for the WHO-led platform. The framework draws on a number of WHO's internationally accepted health systems norms. The foundations for measurements, in the input, output and cross cutting domains were derived from WHO's six building blocks. WHO's three intrinsic goals/outcomes of the health system-health improvement, fairness in financial contribution and responsiveness-were used as the performance goals. The selection of indicators was guided by WHO's toolkit recommended for health system performance measurement for health system strengthening. In addition, the domains of responsiveness are also based WHO-agreed domains.

The indicators conform to the building blocks, whereas the goals of the health systems do not strictly fall under the building blocks' rubric. Different indicators within the domains need to be used for assessing performance towards these goals. The Heartfile framework attempted to address this issue through a two-stepped approach. In Step 1, indicators relevant to assessing health systems performance in Pakistan were inventorized in each of the six health systems domains (Table 1). These indicators were taken from a previous Heartfile-led effort, which tracked health indicators since the country's inception. The list is in conformity with the list of indicators in WHO's tool kit. Step I also enabled mapping of data sources and outlined the need for information collection in new areas. Useful insights were provided by Heartfile's publication, as it had also concomitantly enabled a review of health information systems to outline gaps.14

In Step II, available indicators were used to assess performance of the health system towards aching health systems goals (Table 2). Existing data sources used, the methodologies applied, and information about new data generated to assess performance is presented in Table 2. Methodological details will be described in detail in a scientific paper and are summarized here.

For the analysis of equity in outcomes, secondary analysis of the 2006-07 Pakistan Demographic and Health Survey (PDHS) was performed. Equity has many measures and assessment parameters. In this analysis, the independent effect of wealth quintiles (as determined by a validated index) on all the reproductive and child health outcome variables included in the PDHS was assessed by using multivariate logistic regression analysis controlling for a number of potential confounding factors. Inequities in reproductive and child health were taken as being illustrative of inequity in health outcomes.

Mixed methods were employed to gather information about fairness in financing. Officially reported figures were used for sources of revenue as reported in the National Health Accounts 2006. Information on government employees and safety nets was obtained from the Ministry of Finance and were based on actual reporting. Information for the publicly mandated private means of financing was obtained from published sources whereas Actual reported data on health expenditure for 77.5% of the employees of federal autonomous agencies was used to derive estimates for employees and their dependants. Marketing surveillance estimates provided data on private health insurance. Annual per-capita out of pocket health expenditures have been derived from monthly per-capita health expenditures reported in the Pakistan Social and Living Standards Measurement Survey (PSLM) report, 2005-06.

With regard to responsiveness, WHO's norms have identified and agreed on various domains.13 In our study, we were able to measure responsiveness on all except autonomy.

Two sources of evidence were used for the analysis of responsiveness. For coverage and co-coverage performance assessment, secondary analysis of the national population based PSLM 2005-06 was performed. 13 performance indicators were grouped under various domains, which were in turn clustered under co-coverages. The latter were used to generate Combined Performance index (CPI). Rankings based on CPI were used to classify districts in performance bands for

assessments of coverage performance. The methodology for has been validated earlier in other developing countries.

A cross-sectional survey of public sector facilities was conducted to assess service quality, availability, data quality and some measures of governance, such as informal payments and absenteeism. Multistage random sampling technique was used in the survey. Data was collected through four structured questionnaires/checklists. Three questionnaires-quality of care assessment; capacity assessment of health facility staff to perform various service delivery functions; and assessment of data accuracy and use of information at district level were implemented by field enumerators in each district. Lot Quality Assurance Sampling (LQAS) technique and LQAS Decision Rule Table was used to assess data accuracy performance in the district. Indicators were grouped under various domains and scores were awarded to each indicator on a decimal scale. Combined percentage performance for quality of care in each domain was calculated by summating the values of data under each domain and a mean value was obtained. Inter-provincial ranking was done for each domain using the combined percentage performance indicator. This methodology has been validated in previous studies.20,21 Reported frequencies of service availability and key governance indicators reflecting responsiveness were additionally reflected as measures of responsiveness.

The framework for health systems performance assessment described herewith has some limitations, of which its inability to access information from the private sector facilities is the foremost. This is important as the private sector plays a major part in the delivery of healthcare in Pakistan. This gap will have to be bridged through representative surveys in the future. As such therefore, at present, the framework is relevant to public health facilities. It has been developed for Pakistan's context, but can be adapted for other developing countries, which have similar information systems in place, from which data can be collated on an ongoing basis. This can be supplemented by yearly field surveys to gather missing information as was the case in Pakistan. The resource requirements of this approach are not extensive and this can be feasible with some additional inputs into the health information system.

Over the years, donors have made investments in setting up health information systems and building capacity in line with their global role in supporting respective instruments. The United States Agency for International Development has

supported the Demographic and Health Surveys (DHS) in 85 countries, the World Bank has promoted the Social and Living Standards Measurement (SLM) surveys in over 60 countries whereas UNICEF has helped institutionalize the Multiple Indicator Cluster Survey (MICS) system in 67 countries. The World Health Organization on the other hand has helped to institutionalize National Health Accounts in over a hundred countries. The framework for health systems performance assessment developed for Pakistan by Heartfile has built further on these information systems and has tapped into them to seek information of relevance to performance assessment. This approach obviates the need for large investments, which are not feasible in the current fiscally constrained environment. In addition, it provides an opportunity to strengthen existing systems and bride their weaknesses. The framework used for Pakistan will need to be adapted for other developing countries that seek to develop similar frameworks.

TABLE 1. INDICATORS RELEVANT TO HEALTH SYSTEMS PERFORMANCE ASSESSMENT AND SOURCES OF EVIDENCE

HEALTH SYSTEMS PERFORMANCE ASSESSMENT DOMAINS	INDICATORS	MEANS OF VERIFICATION
1. SERVICE DELIVERY		
Service availability	Number and distribu- tion of health facilities per 10,000 population	Health and Education Atlas (2002), updated with provincial Director General Health's records
	Number and distribution of in-patient beds per 10,000 population	lbid
	Availability of services at the Primary Health Care level (Antenatal care, Skilled Birth Attendants, immunization, family planning, minor curative services)	New facility level data

HEALTH SYSTEMS PERFORMANCE ASSESSMENT DOMAINS	INDICATORS	MEANS OF VERIFICATION
Service Quality	Combined performance index for quality of care based on a list of indicators in the domains of infrastructure, resources, knowledge, community satisfaction, data accuracy, staff capacity, service availability and health information system performance.	New facility level data
Service Coverage	Combined performance index for coverage of care based on a list of 13 indicators	Pakistan Social and Living Standards Measurement Survey 2006-07
2. FINANCING	Yearly expenditure on health by the public and private sectors	Mixed methods employing data from the National Health Accounts, source information, estimates and triangulations
	Yearly per-capita expenditure on health by the public and private sectors	
	Percentage of the GDP spent on health by the public and private sectors	
	Percentage of the population receiving financial coverage for health	
	Percentage of contributions by various sources of collection	

HEALTH SYSTEMS PERFORMANCE ASSESSMENT DOMAINS	INDICATORS	MEANS OF VERIFICATION
	Ratio of household out-of-pocket payments for health to total health expenditures.	
3. HUMAN RESOURCE	Number of health workers per 10,000 population	
	Distribution of health workers by profession/ specialization, region, place of work and gender	
4. GOVERNANCE	Health worker absenteeism in public health facilities	New facility level data
	Proportion of government funds which reach district-level facilities	
	Stock-out rates (absence) of essential drugs in health facilities	
	Proportion of informal payments within the public health care system	
	Proportion of pharmaceutical sales that consist of counterfeit drugs	Drug store survey
5. INFORMATION SYSTEMS	Performance on reporting, data quality, coverage, timelines, use of Information	New facility level data
6. MEDICINES AND TECHNOLGIES	Stock out of essential tracer drugs	New facility level data

TABLE 2. SOURCES OF EVIDENCE FOR HEARTFILE'S HEALTH SYSTEMS PERFORMANCE ASSESSMENT FRAMEWORK

HEALTH SYSTEMS PERFORMANCE OUTCOMES	DATA SOURCES	TYPE OF ANALYSIS	METHOD
Equity in health outcomes	Pakistan Demographic and Health Survey (2006-07)	Secondary	Multivariate logistic regression analysis
Fairness in financing	-		
	National Health Accounts	Secondary analysis	Mixed methods
	Government agency sources	Primary data	
	Pakistan Social and Living Standards Measurement Survey (2005-06)	Secondary analysis	
Responsiveness		·	
Service availability	Field Survey (2009)	Primary	Reported frequencies
Service coverage and utilization	Pakistan Social and Living Standards Measurement Survey (2005-06)	Secondary	Rankings based on CPI
Service quality (physical infrastructure; input and resources; knowledge; community satisfaction; data quality)	Field Survey (2009)	Primary	Combined performance rankings and
LOT quality assurance sampling			
Governance indicators reflecting responsiveness	Field Survey (2009)	Primary	Reported frequencies

* Nationally representative field survey of Primary Health Care facilities

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PARAL SION 2

TRACKING COUNTRY HEALTH SYSTEMS PERFORMANCE INSTITUTIONALIZATION OF MONITORING HEALTH AND HEALTH SYSTEM PERFORMANCE IN THAILAND

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1. BACKGROUND

There is considerable interest in measuring the performance of health systems world-wide.¹ In developed countries, primary concerns about health system performance include costs, equity in access, quality of care and patient safety, and how to tackle the long-term implications for health systems of ageing populations together with prevention and management of chronic diseases. In the developing world, it is increasingly recognized that health systems constraints in terms of financial resources and human resources for health² have restricted progress towards the MDGs.³ Moreover, an emerging health transition and a double burden of both communicable and non-communicable chronic diseases result in a need for more resources and effective management of the health systems in developing countries.

Thailand is a lower-middle income country embarking in health system reforms, and its health systems have been continuously monitored and assessed by organizations and institutes both in and outside the health sector for years. Objectives of health system performance assessment (HSPA) in Thailand comprises: a) to assess performance and achievements of the country's investment in the health system; b) to improve management and accountability of the responsible institutes/organizations involving health sector reforms, c) learning to do better by assessing the gap between achievements and national health goals or international benchmark; and d) to identify key challenges of the health system reform and gaps in data quality.

¹ Boerma T, Chopra M, Evans D. Health systems performance assessment. Editorial comment. Bull WHO 2009.

² Chen L, Evans T, Anand S, Boufford J, et al. Human resources for health : overcoming the crisis. Lancet 2004; 364: 1984-90.

³ <u>Travis P, Bennett S, Haines A, et</u> al. Overcoming health-systems constraints to achieve the Millennium Development Goals. Lancet 2004;364:900-6.

To monitor and evaluate the health care systems in Thailand, it is also necessary to take into account the time factor and explore the short and long term benefits from HSPA. For the short term benefits, HSPA demonstrates what Thais are getting from the increased inputs and the country's recent reform policies. For long term expectations, it answers two questions: a) whether health sector reforms have the effects on improving access, quality, coverage, financial protection, equity in health, and patient satisfaction over time; and b) whether these health sector reforms result in health impacts that reduce mortality and morbidity, and improve health status of the Thai population.

2. FRAMEWORK FOR HSPA IN THAILAND

From these objectives of HSPA, Thailand has employed the WHO framework of six building blocks for health system strengthening⁴ to develop assessment in four major indicator domains: 1) system input & processes, 2) outputs, 3) outcomes, and 4) impact. System inputs, processes, and outputs reflect health system capacity; whereas outcomes and impact reflect health systems performance, see Figure 1.

Figure 1: General framework for monitoring and evaluation of health system reform and strengthening



Monitoring & Evaluation of health systems reform /strengthening A general framework

Source: Boerma T. Implications of the findings of the 2008 National Health Services Survey for monitoring & evaluation of the health sector reform in China. 2009.

⁴WHO. Everybody Business: Strengthening health systems to improve health outcomes: WHO's framework for action. 2007, Geneva, World Health Organization.

It is noteworthy that measurement strategies in terms of data sources should be considered in conjunction with the indicator domains. For example, data from National Health Accounts (NHA) can be used for tracking the flow of financial resources which is an important component of the input and process domain. Also, data from administrative reports regarding infrastructure, equipments, human resources, medicines, and health technologies are important data sources for the input and process domain. For other indicator domains, civil registration and vital statistics are useful data sources for impact assessment because these data can reflect health status and outcomes of the population from health system performance. In addition, population-based surveys in Thailand such as Household Health and Welfare Survey (HWS), Household Socio-economic Status Survey (SES), Multi Indicator Cluster Survey (MICS), contains some household and individual data that can be used for assessing health outcomes and impacts in Thailand. Apart from health-related data, these household surveys also contain some socio-economic parameters which can be used for rich-poor categorization in health equity monitoring.

Data analysis and synthesis is considered as an integral part of the framework because this can be used for data quality assessment, projections and estimation, in-depth studies and dissemination of research results. In addition, time-series and trend analyses can be used for assessing the progress and performance of the health systems in Thailand such as NHA series in Thailand from 1994 to 2008 and health equity monitoring prior to and after achieving universal coverage.

Communication and use of health information systems is a very important domain which does not refer to routine reporting systems only, but also includes dissemination of research findings, communication to policymakers, and regular participatory review processes of health strategic planning in many Asian and African countries. Apart from using an evidence-base for policy makers' decision making, this domain also links with global reporting for example World Health Statistics, and Global Burden of Disease, etc.

From this general framework of HSPA, existing reports and facility-based data as well as household and population-based surveys in Thailand are reviewed and mapped in order to identify availability and gaps of data for assessing four indicator domains of HSPA, as shown in Table1. It is clear that Thailand has a number of household survey data and routine information from many institutes and organizations to assess almost all areas of health system capacity and its performance, except governance and health system responsiveness. These two missing areas, therefore, require more efforts from data producers in collaboration with data users in Thailand to develop appropriate tools and approaches for generating evidence to monitor and assess health system performance in these two areas.

			dul	nt				Outp	out		Outco	ome		lmpa	act	
	HCF	HRH	Infra	Gover	Med/	SIH	access	quality	safety	efficiency	Interven	Risk	т	Res	Equity	Finan
			structure	nance	health tech						coverage	factors	outcome	ponsive		protection
Civil registration																
and vital statistics													>			
Biennial SES	>														1	<
Biennial HWS							>					>	>		1	
Census / SPC		>											>			
NHES												>	>			
MICS							>				>		>		>	
NHA	>														>	
Facility-based report	>							>	>	>	>					
H resource survey		>	>		>						>					
HIS electronic IP																
database						>		>								
Dis surveillance						>										
Behavioral H																
survey												~				
Sero-sentinel																
Survey												>	>			
Specific dis																
registration													>			
Quality assurance																
(HA)							>	>						>		
Note: SES = househol	d soci	o-ecor	nomic sur	vey, HV	VS= Hea	alth an	d Welfa	e surve)	, NHES	= Nation	al Health	Examinat	ion surve	, MICS =	Multiple	Indicator
Cluster survey, NHA =	Natior	ial Hea	alth Accol	unts, H⊬	V = HOSD	ntal ac	creditati	on								

Table 1: Data available for tracking health system performance in Thailand

3. COMPLEXITY OF HIS IN THAILAND AND INVOLVEMENTS OF KEY STAKEHOLDERS

The health information system in Thailand is not a single system, but it consists of multiple sub-systems of health information with involvement of many key stakeholders in and outside the health sector. For example, the mortality data from civil and death registration which are routinely used as the main data source of mortal statistics are regularly transferred from the Ministry of Interior to the Ministry of Public Health (MOPH) through the nationwide online system. Another example is the population-based and household surveys regularly conducted by the National Statistical Office (NSO) of Thailand. These surveys cover data on household socioeconomic status and health related information of individuals which are widely used by MOPH, National Health Security Office (NHSO) and other research institutes in Thailand to monitor health system performance in the areas of health care financing, distribution of health outcomes and risk factors, and financial risk protection, and the impact of health reform policies, particularly the implementation of the universal coverage policy in 2002.

The series of National Health Accounts (NHA) of Thailand from 1994 to 2008 is another example of involvement from many stakeholders in developing information about flows of financial resources for health in the country. The development of NHA received collaboration and contribution from many organizations and stakeholders to generate and collect data on health care finance at household and institutional levels. The working group of Thai NHA comprising representatives from various institutes has been set up and modified from time to time since the first phase of NHA in 1994. Data of household spending on health has been collected from national household surveys conducted by NSO, whereas data on government spending on health of MOPH, NHSO, Thai Health Promotion Foundation, and health care providers has been collected by representatives from many organizations and the working group members.

There are multiple sources of finance for developing health information systems in Thailand. The major source of finance is the government budget which most public organizations such as data producers e.g. NSO, MOPH, and health care purchasers e.g. NHSO, SSO, and Comptroller General Department (CGD), receive from the government annually and use for maintaining a number of vital health information. Another source of finance is the budget from Thai Health Promotion Foundation (THPF) which is an autonomous organization which receives an earmarked 2% additional tax from tobacco and alcohol consumption. THPF has allocated budgets for the Health Information program System Development Office (HISO) to coordinate and develop a network of HIS key stakeholders in Thailand for a couple of years, see Figure 2. The final financing source for HIS is direct payments from data users, either public or private organizations to data producers when these organizations require either raw data or additional information to be added into the existing population-based surveys. However, so far there is no assessment about the share of each financing source for HIS in Thailand.

Figure 2: Key stakeholders and structure of HIS Development in Thailand



Structure of Health Information System Development Plan in Thailand

Source: modified from Health Information System Development Office (HISO)

4. NETWORKING AND MANAGEMENT FOR HSPA IN THAILAND

Regarding the complexity of the health information system in Thailand, a national plan of HIS development has been developed aiming to coordinate and network different key stakeholders of HIS in the country. This networking and administrative function is operated by Health Information System Development Office (HISO) and financed by THPF with technical support from MOPH and HSRI, see Figure 2. The mission of the HIS Development Plan is to support the continuous process of HIS development in the country through an emphasis on user demand and networking process among key stakeholders. The aim is that collaboration among key partners will lead to the learning process, standardization, mutual interest, and an effective way to promote use of HIS with continuous improvements. In addition, this national development plan supports networks of the HIS subsystems such as NHA network, BOD network, health information network of HRH, and collaboration between NSO and data users (e.g. MOPH, HSRI, and NESDB) in improving population-based household surveys in Thailand.

5. KEY FACTORS CONTRIBUTING TO INSTITUTIONALIZA-TION OF HSPA IN THAILAND

Lessons from Thailand indicate that there are a number of key factors contributing to success in improving HSPA institutionalization. These key factors are:

- a) Gradual evolving culture among policy makers in using evidence for decision making, particularly prior to and after implementation of the universal coverage policy in 2002 ⁵;
- b) Increasing demand for HIS for decision making e.g. policymakers in NHSO and MOPH, health strategic planners, directors of policy and planning division, researchers, etc;
- c) Adequate financing from various sources of finance and skilful human resources for HIS in many public organizations such as NSO, NHSO, and NESDB;
- d) Long-term capacity building and skills in data generation, compilation, processing, synthesis & analyses, dissemination, communication to the public and policymakers of some public institutions;
- e) Good collaboration and close relationship between data producers and data users, and policymakers ⁶;

⁵Tangcharoensathien V, Wibulpolprasert S, Nitayarumphong S. (2003) 'Knowledge-based changes to health systems: the Thai experience in policy development', Bulletin of the World Health Organization, 82 (10): 750-6. ⁶Tangcharoensathien V, Limwattananon S, Prakongsai P. Improving healthrelated information systems to monitor equity in health: lessons from Thailand. In McIntyre D and Mooney G eds. The Economics of Health Equity. Cambridge University Press. 2007. pp 222-6.

f) Networking at sub-national, national, and international levels, for example, the development of sub-national NHA at the provincial level, and international collaboration between HISO and Health Metrics Network (HMN).

6. REMAINING KEY CHALLENGES IN INSTITUTIONALIZING HIS IN THAILAND

Despite the continuous and long-term development of HIS, some key challenges in the further development and institutionalization of HIS in Thailand still remain. These challenges are:

- a) There are many HIS institutes/organizations responsible for different components of HSPA in Thailand which leads to duplication, inefficiency, and difficulties in networking and standardization ⁷;
- b) To some extent, there are gaps in data quality and data availability, particularly data of the private sector;
- c) Despite adequate financing to maintain and operate HIS in Thailand, more investment in HIS both human and financial resources in many institutions for further development are needed, for example, the panel household surveys of NSO, MICS round 4, etc;
- d) Variations in level of technical and institutional capacity in data generation, compilation, data processing, data analysis & synthesis, and communication, in some public institutes;
- e) Problems in standardization of data generation, collection, and analyses;
- f) Low utilization of evidence from HIS by some policymakers, but tends to be improving; and
- g) There is a need for building and fostering long term capacity of HIS in order to have champions in each component and area of HSPA in Thailand.

7. PRIORITY AREAS AND EXPECTED OUTPUTS FOR HIS DEVELOPMENT STRATEGIC PLAN OF THAILAND

To sustain and strengthen institutional capacity of HIS in Thailand, three areas of strategic planning for HIS development will be further developed.

⁷ Faramnuayphol P. Thai health information system: situation and challenges. In Health Systems Research Institute (HSRI) ed. Never Ending Stories of the Development of an effective HIS in Thailand. Health Systems Research Institute of Thailand. 2010. pp 3-9.

- 7.1 Improving organizational capacity and enabling environment for HIS development through:
 - a) Create platforms and strengthening network of institutions responsible for HIS at central, regional, and provincial levels,
 - b) Clearly define roles and responsibilities of institutions involving in HIS at different levels in order to avoid duplication of work,
 - c) Allocate adequate financial and human resources for sustaining and further developments of HIS in the country.
- 7.2 Improving technical design of HIS which include:
 - a) Develop and have a consensus on a set of national health indicators related to HSPA;
 - b) Standardize essential data for HSPA among different key stakeholders;
 - c) Develop guidelines and tools for data generation, compilation, synthesis, and reporting;
 - d) Develop tools for information management and use of HIS in the country.
- 7.3 Improve behaviour in using data and HIS in the country which includes:
 - a) Create conducive environment to improve motivation of all stakeholders to implement and utilize HIS effectively;
 - b) Increase more skilful personnel involved in HIS at all levels through deployment and training;
 - c) Create opportunities for pre- and in-service training of HIS for health personnel.

8. CONCLUSIONS

This short paper describes the objectives of HSPA in Thailand and the general framework for assessing health system performance of the country. Available and missing data for assessing health system performance using WHO framework on six building blocks are also explored and mapped. It is found that governance and responsiveness are two missing areas of HSPA that need to be further developed in HIS in Thailand. Lessons from HSPA in Thailand indicate that key contributing factors include demand for HIS from policymakers and changes in their behaviors to use evidence for decision making. Adequate financing, networking, and skillful human resources and long term capacity building with good collaboration between data producers and data users are also key contributing factors. The remaining key challenges in institutionalizing HIS in Thailand include difficulties in networking, and standardization of data generation, collection, and data analyses among many HIS institutions. Gaps in data quality and availability, particularly the private sector, and long term capacity building in each component of HSPA are other challenges that need to be addressed.

9. ACKNOWLEDGEMENT

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ZAMBIA: STRENGTHENING THE ANALYSIS FOR ANNUAL HEALTH SECTOR REVIEWS THROUGH DISTRICT ASSESSMENTS

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ZAMBIA, like many sub-Saharan African countries continues to bear a huge burden of disease mainly due to communicable diseases such as HIV/AIDS, Malaria, Tuberculosis, etc. Recently this disease burden has been compounded by a marked change in the epidemiological profile as a result of emerging diseases of life-style such as Diabetes, Hypertension, etc. Therefore the demand for better health care delivery systems in Zambia has increased, with increasing utilization levels and pattern of services ,

The current National Health Strategic Plan (Yrs. 2006-2010), provides a strategic sector development framework for Government, Cooperating Partners, Civil Society organizations and civil society, and indeed the citizenry to harness existing resources, and cost-effectively deploy them to areas of greatest impact. Sector policy dialogue that facilitates investment towards improved services delivery and the realization of the national health vision is being implemented on the premise of Sector Wide Approach (SWAp) platform in Zambia. SWAps have remained a cornerstone in facilitating attainment of the national health goals, as well as the Millennium Development Goals (MDGs).

To provide Zambians with equity of access to quality and cost-effective health care as close to the family as possible, is the national health vision that has provided oversight to the implementation of three (3) successive sector strategic plans previously. Over the years of investment, Zambia, recently reported significant improvements in most impact health indicators. Table 1 below provides an outline of progress made so far on selected key health impact indicators.

No.	Indicator	Yr. 2002	Yr. 2007
1	Infant Mortality	95	70
	(per 1000 Live Births)		
2	Under Five Mortality	168	119
	(per 1000 Live Births)		
3	Maternal Mortality	729	591
	(per 100,000 Live Births)		
4	HIV/IADS Prevalence (%)	16.3	14.3
5	Vaccination coverage (%)	70	68

TABLE 1. KEY HEALTH SECTOR INDICATORS

The progress reported in Table 1, has not been attained without many challenges in terms of building robust systems necessary for accelerating implementation. These challenges have remained mainly across the need to strengthen the six building blocks for an efficient and cost-effective health care delivery system in the country.

COUNTRY EXPERIENCE IN IMPLEMENTING THE SIX BUILDING BLOCKS IN ZAMBIA IS AS OUTLINE BELOW.

FINANCING

The Ministry of Health, jointly with sector Cooperating Partners have developed mechanisms for strengthening health care financing in Zambia. The health Budget receives funding through both sector-direct and General Budget funding. In order to ensure effective allocation of funds and other resources within the SWAp framework at sector level, the Ministry of Health has been operating a resource pooling mechanism through basket funding modality for allocation, disbursement and accounting. The health sector developed and adopted a Financial, Administrative and Management System (FAMS) that was meant to support implementation of the basket funding mechanisms. FAMS has been implemented in order ensure standardization on financial management, expenditure reporting and accounts, by all health institutions that have been benefiting from basket funds.

Development and sector-wide expansion of the basket funding mechanisms in the health sector have been driven by the aspirations of the sector to deliver a Basic Package of health care at all levels. In order to support this effort, funds disbursed to lower levels of care have been accounted for through the FAMS reporting system. Districts and other health institutions benefiting from the basket funds were trained in FAMS, as a precondition, in order to enable them generate financial reports using Computerbased Accounting software called Navision®. Data collected from the FAMS reporting format using Navision® has been primarily financial, covering: funds (revenue) received by the institution from various sources including non-basket support, expenditures incurred, any financial carry-overs, institutional debt management and balance of payments at the time of reporting.

Generally these data have been of acceptable standard. Reports generated from the FAMS have been used to facilitate sector policy dialogue on effective financing of the sector policies and strategies. These reports have been submitted monthly to the national level, but records are made available whenever necessary.

Government of the Republic of Zambia, through the Ministry of Finance has currently embarked on a programme to reform and strengthen Public Expenditure Management and Financial Accountability (PEMFA). And through PEMFA a new system has been introduced called Integrated Financial Management Information System (IFMIS). It is hoped that PEMFA and the institutionalization of IFMIS will improve efficiency, effectiveness and accountability in the management and use of public financial resources to support the implementation of Zambia's National Development Plan (NDP).

HEALTH WORKFORCE

The health sector in Zambia, like most sub-Saharan African countries has suffered from severe shortage of health workforce. Currently staffing levels of core health workers (Physicians, Nurses, Midwives, and Paramedics) is estimated at 50% in public and mission health facilities, with a distinct divide between rural facilities having lower levels when compared to urban facilities.

Poor staffing levels in public and mission health facilities have led to increased staff workload. For instance health centre staff (qualified) daily contacts have increased from 17.4 in 2005 to 18.2 in 2006. This has led to poor quality of service delivered.

INFORMATION

There are mainly two sources of information in the Zambian health sector, namely: population-based surveys and health facility-based routine data sources.

For sometime now, the health sector in Zambia has consistently undertaken population-based information surveys, though this has not been without major policy and operational challenges. Firstly in terms having a robust national statistical policy and strategy, Zambia till 2002, lacked a forward looking national Statistical Policy and Strategic Plan that informs development processes and indicator performance. As a result of inadequate policy and strategic direction, Central Statistical Office (CSO) which is the mandated national institution for coordinating national census and statistics as provided for by the Census and Statistics Act of 1964, faced major challenges in carrying out this task. For instance, although the Act is explicit on the mandate of the Director of the CSO to generally organize a coordinated scheme of social and economic statistics relating to Zambia, there is not clear mention of the financing modalities for these surveys. Therefore the Strategic Plan of 2003-7 was a deliberate effort to meet the increasing demand for development indicator reporting under the Poverty Reduction Strategy Paper (PRSP) 2002-2004, Transitional National Development Plan (TNDP) 2002-2005, and the Fifth National Development Plan (NDP) 2006-2010, through improved organizational arrangements and funding for the planned census and population surveys

Ministry of Health entered into a Memorandum of Understanding (MoU) with CSO in 1991 in order to facilitate conducting of the first Zambia Demographic and Health Survey (ZDHS) of 1992. The quality of the ZDHS generated data and indicators have remained good relatively. However with improved funding, these data could be more representative with sample frameworks applicable for sub-national level utilization of findings.

For facility-based routine health information sources, Zambia has been implementing a Health Management Information System (HMIS) in all the public health facilities since 1998. In 2005 an indepth appraisal of the HIMS in Zambia was conducted using Health Metrics tools. The appraisal report provided evidence for formulating a Plan of Action to revise and strengthen the HMIS for poverty reduction monitoring in the health sector. The European Commission (EC), through the

Poverty Reduction Budget Support (PRBS), provided funding, that has been used to undertake five major interventions to improve the quality of the current Zambian HMIS. The five major deliverables have been: (i) the re-designing of the system itself with emphasis on responsiveness and flexibility, and defining a core indicator set alongside sector policy priorities; (ii) improving skills of users through the development of both in-service and pre-service HMIS training curricula; (iii) strengthening data utilization, and research; (iv)quality assurance and control including timely monitoring and evaluation; and (v) strengthening capacity in data management and communication.

Efforts to improve both population-based data sources and facility-based routine data sources are being coordinated under the framework of strengthening a comprehensive national Health Information System (HIS). In collaboration with key sector partners at country-level and the HMN Secretariat in Geneva, a robust HIS Strategic Plan 2009-2015 has been developed, based on the HIS Assessment Report, that will provide strategic direction for investment in the Zambian HIS.

MEDICAL PRODUCTS AND COMMODITIES

Following recommendations of the sector strategic plan Mid Term Review Report (MTR) of 2004, Ministry of Health together with Cooperating Partners, established a drug supply budget line (DSBL) mechanism, which is a dedicated procurement and supply chain management system for medical products and other commodities. Following the establishment of the DSBL, the Ministry has embarked on developing a system that would improve efficiency in procurement, storage and distribution of medical supplies and other products essential for health care provision.

SERVICE DELIVERY

Medical service delivery in Zambia is essentially at three levels, namely: primary health care (district level), second referral (provincial level), and tertiary level (specialist/national level).

The HMIS provides a good coverage of health service indicators at primary health care, which includes health centres and district hospitals (first referral health facilities). The following Service delivery registers are usually found at this level of care: Out-Patient Department (OPD) register, In-patient Department Register (IPD), Maternal Delivery Register, Safe Motherhood register, Child Health Register, HIV/AIDS registers, Laboratory Register, Pharmacy Drug Logbook.

GOVERNANCE

Under the current health sector strategic plan, governance is meant to develop comprehensive policy and legal frameworks and robust support instruments and mechanisms for effective coordination, implementation and monitoring of health services.

In 2005, Government through the Ministry of Finance developed a common Performance Assessment Framework (PAF) whose key result is to monitor sector policy support and implementation of poverty reduction interventions. The PAF was developed jointly with like-minded Donors in pursuance towards improved policy dialogue for the general budget support; alignment and harmonization towards effective sector programme support. The PAF has been implemented as an instrument for wider-harmonization in practice under the framework of the Joint Assistance Strategy for Zambia (JASZ). Coupled with the PAF, has been a mid-term review of the National Development Plan that provides an opportunity for critical sector performance review in a broader sense of national development framework.

In order to facilitate policy dialogue at sector level, Ministry of Health together with sector Cooperating Partners, undertakes joint sector reviews regularly. These joint sector reviews and other facility-based surveys provide an important opportunity for harnessing semi-permanent data into a data warehouse at both district and national levels.

JOINT ANNUAL REVIEWS

The health sector in Zambia has successively conducted Joint Annual Reviews since 2006, meant to assess performance of the health sector the previous year. The Joint Annual Review (JAR) is implemented within the SWAp framework and is meant to support sector policy dialogue. The JAR is conducted every first quarter of the proceeding year in order to determine performance of the previous year. Performance is measured against a jointly agreed set of Benchmarks. These benchmarks are mainly in three categories: input, process, and output. Inputs such as Medical drugs supplies, Human Resources, Transport and Communication are assessed. Each JAR has identified thematic areas that are given particular focus, with an indepth assessment and analysis of performance. The JAR provides an important input to HMIS Data Quality Audits (DQA).

PERFORMANCE ASSESSMENT

In order to facilitate technical support to the health facilities at all three levels of health care delivery in Zambia, Ministry of Health undertakes periodic (quarterly) Performance Assessments (PA). The purpose of PA is to assess performance of public and mission health facilities over a given period of time in order to provide the necessary technical support for addressing the identified bottlenecks. Semi-permanent data is captured using the PA tool from facilities. The data ranges from service delivery input indicators (stock-outs of medicines and vaccines) to outputs (vaccination coverage, supervised deliveries, etc).

PA also provides an important opportunity for Data Quality Check (DQC) in the routine HMIS registers and reports.

MEDIUM TERM REVIEWS

Half-way the full implementation term of the National Health Strategic Plan, Ministry of Health together with Cooperating Partners undertakes an independent Mid Term Review (MTR) of the sector performance. The purpose of the MTR is to appraisal mid-term implementation and performance of the health sector against set targets in the sector investment plan. Recommendations from the MTR are used to inform accelerated implementation of the sector priorities, through a review of various service delivery support systems. The first MTR was conducted in 2003 in order to review mid-term performance of the NHSP 2001-5. The second MTR was successfully carried in 2008 in order to review performance of the NHSP 2006-2010.



TEA COLLINS

SENIOR HEALTH SYSTEMS SPECIALIST GLOBAL FORUM FOR HEALTH RESEARCH

Dr Téa Collins is Director of Research and Programmes at the Global Forum for Health Research in Geneva, Switzerland. She is also a member of the WHO Secretariat coordinating the work of the First Global Symposium on Health Systems Research for Universal Coverage.

Dr Collins started her career as a physician, working as a pediatrician in Georgia and Russia. After the fall of the Soviet Union, Dr Collins joined the team of reformers in Georgia and served as advisor to the Ministry of Health, coordinating teams of experts developing new health financing mechanisms and social insurance. Following her time with the government she managed technical assistance for the \$20 million World Bank Health Reform Project in Georgia, then served as Regional Health Coordinator for Save the Children in the Caucasus, supervising USAID-funded programs in primary health care and health education.

Dr Collins received a Doctor of Public Health degree from The George Washington University, her dissertation focusing on access to healthcare services among displaced women. She also taught graduate and undergraduate courses at GWU in subjects ranging from international health and development to health systems in Eastern Europe and the former Soviet Union. She received her medical degree from the Georgia State Medical University and earned two master degrees, a Master of Public Health in International Health from Boston University and a Master of Public Administration degree in Public Policy and Management from the Harvard Kennedy School. Dr Collins was a Presidential Scholar and Public Service Fellow at Harvard. Her research and publications have covered topics such as globalization and access to health care services, health policy analysis, health reform, health finance, and evaluation of health systems performance.



CANDY DAY

TECHNICAL SPECIALIST HEALTH SYSTEMS TRUST

Candy Day is a pharmacist with a Masters in Clinical Pharmacology and subsequent training in medical informatics through the International Training in Medical Informatics fellowship. She has worked as a pharmacist in the retail, hospital and academic sectors, always involved at some level in the data and information systems supporting this work. Over the past 13 years (part-time) she has worked on developing electronic information resources in the field of public health. This started out with a focus on provision of connectivity and infrastructure, web sites and email dissemination & discussion groups. A specialised health indicators database has been developed, and a web-GIS system implemented to monitor district health indicators. Increasingly we are also analysing large datasets of routine data to update important health indicators. She has also been a co-author of the annual chapter on Health Indicators in the South African Health Review (SAHR) and the District Health Barometer, which provides a district-level view of health system performance. In addition she has collaborated with the National Department of Health and various groups undertaking cost-effectiveness analysis, health information system performance assessment and other quantitative analyses of the health system.



DANIEL LOW-BEER

UNIT DIRECTOR PERFORMANCE, IMPACT AND EFFECTIVENESS THE GLOBAL FUND TO FIGHT AIDS, TB AND MALARIA

Dr. Daniel Low-Beer is Director of Performance and Effectiveness at the Global Fund, where he has worked since 2004, leading performance based funding, aid effectiveness and results. He worked in WHO at the Global Program on AIDS in the early 1990s in Global AIDS surveillance and evaluation, and providing the scientific evidence behind early HIV prevention successes in Uganda and Thailand, behaviour and communication changes, the first demographic impact of AIDS, and led the first Global Burden of HIV study. He subsequently worked in strategy consulting, as Director of the health and population evaluation unit at Cambridge University, and in HIV prevention in Southern Africa. He has worked with Ministries of Health in Africa and Asia, as well with USAID, DFID, Johns Hopkins Centre for Health Communication, NGOs in South Africa, and the OECD executive committee on aid effectiveness.



SANIA NISHTAR

PRESIDENT & CEO HEARTFILE ORGANIZATION

Sania Nishtar is the founder and president of the NGO think tank, Heartfile, which today is the most powerful health policy voice in Pakistan and is recognized as a model for replication in other developing countries. Her areas of interests are health systems reform, broader issues of governance and public-private relationships, reorientation of priorities in health and global health.

In Pakistan her work in the health sector has inspired new initiatives and has shaped policies on health reform and non-communicable diseases. She is also the founder of Pakistan's Health Policy Forum and provides support to many agencies in an advisory role. Within Pakistan, she is also a voice to catalyze change at the broader governance level as a weekly op-columnist in Pakistan's largest English newspaper. She additionally sits on many governing boards and is a visiting faculty to many educational institutions.

Internationally, Sania Nishtar is a member of many Expert Working Groups and Task Forces of the World Health Organization and is currently a member of the board of the International Union for Health Promotion and the Alliance for Health Policy and Systems Research. She is also a member of the World Economic Forum's Global Agenda Council, the Clinton Global Initiative, the Ministerial Leadership Initiative for Global Health and many other international initiatives. She has formerly been on several international Boards, and has chaired several global campaigns and programs. She has also been an advisor to WHO on numerous occasions, has published over 100 journal articles and is the author of 4 books. Her book on Health Reform entitled 'Choked Pipes' will be released by Oxford University Press in February 2010.

She speaks to audiences around the world and has been extensively published in and quoted in the media. Sania Nishtar is the recipient of Pakistan's Sitara-e-Imtiaz, the European Societies Population Science Award and 16 gold medals. She was named as the International Health Professional of the Year 2007 by the International Biographical Centre, Cambridge

Sania Nishtar holds a Fellowship of the Royal College of Physicians of London and a Ph.D. A detailed profile can be accessed at http://www.sanianishtar.info


PHUSIT PRAKONGSAI

SENIOR RESEARCHER/MEDICAL DOCTOR INTERNATIONAL HEALTH POLICY PROGRAM (IHPP) THAILAND

Phusit Prakongsai, MD degree from Mahidol University, Thailand (1988), Certificate in Preventive Medicine from Thai Medical Council (1993), PhD in Public Health and Policy from London School of Hygiene and Tropical Medicine (2008). Ten years of field experiences in public health and health service management at three district hospitals in the rural area of Thailand (1988 – 1998). He has been the principal investigator of several research studies on health policy, health insurance, and health care finance at the International Health Policy Program, Thailand since 1999. The topic of his PhD thesis topic was "The impact of the universal coverage policy on equity of the Thai health care system". His research interest falls into health equity, health insurance, health economics and financing.



CHRISTOPHER SIMOONGA DEPUTY DIRECTOR FOR MONITORING AND EVALUATION MINISTRY OF HEALTH ZAMBIA

I am a Monitoring and Evaluation Expert with over 11 years of practical experience in developing Health Information Systems (HIS) and tools for effective health systems and services planning, implementation and performance monitoring and evaluation at regional, national and sub-national levels. In achieving this experience, I have worked very closely with various development partners, government and communities, bilateral and multilateral partners within Zambia, and in the region.

My strong focus has always been on developing monitoring and evaluation systems and tools that generate quality evidence for decision-support in efficient allocation and management of resources, effective performance tracking against programme objectives and agreed targets. For Zambia, this effort has demonstrated positive results at sector-level in that todate the National Health Sector Strategic Plan (NHSP) contains a strong monitoring and evaluation strategy, a facility that has attracted investment-support by both bilateral and multilateral Development Partners due to improved accountability of resources. And through joint mechanisms for monitoring and evaluation of health sector investment under the Sector-Wide Approach (SWAp) framework, this strategy has been fully operationalized.

Recently I have also concentrated on institutionalizing monitoring and evaluation systems and strategies that are meant to measure sector-performance towards the fifth National Development Plan, and achievement of Millennium Development Goals in Zambia. This effort has strengthened the case for increased allocation of resources to the health sector under the General Budget support framework at the Ministry of Finance.

I have also effectively coordinated sector-level domestication of global and regional initiatives, such as the Global Fund for HIV/AIDS, TB and Malaria (GFATM), Roll Back Malaria, Global Alliance for Vaccine Initiative (GAVI), Health Metrics Network (HMN), and indeed Millennium Development Goals (MDGs), aimed at poverty alleviation.

During implementation of these processes, I have acquired analytical skills in the design and application of resource allocation

tools under MTEF, policy development cycle, human resources management and development, income and expenditure tracking, spatial epidemiology, diseases surveillance including EPI, HIV/AIDS, Malaria and Tuberculosis, as well as the public health aspects of Health Impact Assessment (HIA) in Development planning.

I have always been interested and committed to the strengthening of Health Information Systems (HIS) both routine and population-based. With support (both technical and financial) from HMN Secretariat, I have successfully coordinated a comprehensive assessment of HIS in Zambia, and further coordinated development of a HIS Strategic Plan for Zambia, which is currently being implemented under Wave One partnership. As a Short Term Consultant for the HMN, I coordinated and finalised the HIS Country Assessment Report for Uganda.

I have also been actively involved in the development and use of both facility-based and population-based information in planning and implementation of public health programmes in Zambia. In close collaboration with the Central Statistical Office (CSO) I have successfully coordinated Demographic and Health Surveys (ZDHS) in Zambia, meant to measure impact of national efforts towards improved population health and poverty reduction.

As a consultant for the World Health Organization/Regional Office for Africa (WHO/AFRO), I have provided technical support to other countries such as Uganda, Tanzania, Malawi, Ethiopia, for strengthening country-level monitoring and evaluation systems within the Roll Back Malaria framework. This has also exposed me to various governance systems ranging from mere de-concentration to full devolution of both service delivery and fiscal powers.

Due to my passion for Human Resources for Health Information development in Zambia and indeed Africa, I have conducted management and professional training courses at tertiary levels in HIS.For instance, lecturing in the Department of Community Medicine at the University of Zambia, responsible for setting-up, teaching and examining Masters of Public Health (MPH) courses in epidemiology, health systems research and Project Management.

Currently I am working in the Ministry of Health in Zambia as a Director in charge of Monitoring and Evaluation, Policy and Planning

Prince Mahidol Award Conference 2010

PARALLEL SESSION 2.2:

FINANCIAL AND HUMAN RESOURCES FOR HIS

Global Health Information Forum

HUMAN RESOURCES FOR HEALTH INFORMATION SYSTEMS IN DEVELOPING COUNTRIES

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ABSTRACT

One barrier to successful implementation of information and communication technology, both in developed and developing counties, has been the availability of a skilled workforce. This paper explores what is known about the workforce related to this technology, which comes mainly from developed countries, since little published data on this topic exist from developing countries. It then proposes solutions for better understanding the knowledge, skills, and competencies required for quantifying workforce needs, especially in the context of local customs, culture, language, and healthcare systems.

INTRODUCTION

Despite unprecedented advances in science and technology for health in the developed world, the developing economies are increasingly left behind. One way to bring these advances to these economies is through the use of information and communication technology (ICT). The reach of ICT in the developing world, both via Internet access and mobile phones, is increasing substantially [1]. The general use of ICT for health applications is called eHealth [2], while its application limited to mobile phone technology is called mHealth [3].

In developed economies, there is increasing evidence, documented by systematic reviews, that ICT can improve the quality and safety of health care while reducing its cost [4, 5]. In developing economies, the evidence is less robust, but they are a number of successful applications from regions such as French-speaking Africa [6], Latin America [7-9], and the Philippines [10].

One of the challenges to implementing health ICT is the need for a skilled workforce that understands healthcare, ICT, and the people and organizational challenges involved. The intersection of these areas is commonly known as the discipline of biomedical and health informatics (or health informatics for short) [11]. There is also growing evidence for the value that a well-trained health informatics workforce can offer [12]. A growing number of educational programs are emerging to meet the need to train such individuals, from graduate education to shorter courses, such as the American Medical Informatics Association (AMIA) 10x10 initiative [13, 14].

Additional solutions in developing countries, however, will involve advancing education for workers [15] and building science capacity [16]. Indeed, a number of initiatives in many countries have been undertaken [17-20]. Some successful programs have involved partnerships with academic centers in developed countries [21].

There are many questions concerning the optimal implementation and meaningful use of ICT in health:

- What are the profiles (i.e., job roles, competencies, and required training) for the workforce needed to lead eHealth projects?
- What are the valid methods for quantifying workforce needs in developing countries?
- How can we account for and be respectful of variations in local perspectives (culture, language, health care systems, existing resources, etc.) in developing countries while advancing ICT solutions?

Certainly any approach to assessing the needs for ICT knowledge and workforce development must focus on the needs of different individuals in the health care system and existing or planned ICT projects of these countries. This includes:

- Citizens/patients basic health literacy, use of technology for improving health and interacting with health care and public health systems
- Health care and public health professionals use of ICT to improve care, interact with citizens/patients, and obtain education
- Health ICT (informatics) professionals development, implementation, and evaluation of ICT to improve health, health care, and public health
- Health leaders and policy makers optimal decision making for investment and usage of health ICT

How do we determine the needs and solutions? The process must be data-driven, using existing research capabilities. As

needs will likely differ among countries, cultures, and political and economic factors, the solutions may differ by country or region. There must be a meeting of the minds among those familiar with understanding of local health priorities as well as ICT capacity and of those who are familiar with ICT and what solutions have been found to be most effective in these settings. From this will emerge solutions for appropriate ICT implementation and education of stakeholders, including the ICT workforce. With this context, we can explore the existing research data on workforce and then propose a framework for further research and educational program development in quantifying and characterizing the ICT workforce needs in developing countries.

Despite the acknowledged importance of a well-trained workforce in successful ICT implementation [22, 23], there is a paucity of actual research to guide needs and development. All of the national-level data comes from developed countries, in particular England [24], Australia [25], and Canada [26]. There are some studies from the United States that have focused on specific segments of the workforce, such as IT professionals [27, 28] and health information managers [29]. Also in the United States, it has been estimated that the EHR adoption goals of the American Recovery and Reinvestment Act (ARRA) legislation will require 50,000 additional professionals [30] deployed in a variety of roles and competencies [31]. Another important segment of the workforce whose role has not been quantified at all is those who work in health informatics (also called biomedical and health informatics or clinical informatics), the discipline focused on the optimal acquisition, storage, and use of information in biomedical and health settings [11].

Even in the developed world, it is essential a more concerted research agenda to better characterize the ICT workforce and its job roles, required competencies, and optimal education. This will not only help ICT leaders implement systems better, but also assist educational programs in determining the best curricula for students training to fill these roles. A major component of this research agenda must include further elaboration of the role of various professionals in the success of ICT implementations. Those with an interest in adoption of ICT in the developing world must also understand the workforce in that setting to assure the most successful implementation.

The understanding of workforce needs in any setting is a challenging task. The first step in understanding workforce

needs is to catalog the types of eHealth and mHealth applications used in specific countries. In developing economies, this might include basic electronic health records and telehealth applications. To understand the workforce currently used as well as that ideally required, it would be necessary to visit representative locations where the applications are used. The first type of data will be purely quantitative, such as the size of each organization, its "product" (e.g., health care, public health, commercial software), and its customer base (e.g., patients, the public, purchasers of software). In the case of the hospitals, we would also need to assess the number of patients, number of beds, and other health care measures. Also, since many health care institutions are tied into public health functions and governments, we will need to understand the specific organization studied in the context of its role in the country's larger health care system.

The next step would be to gather data on the sites' ICT organizations. This would not just include the formal organization, but all who play any sort of role in the provision or support of information or its systems. For example, we would include such individuals as health information managers and librarians as well as any clinicians who are involved in ICT support. We also need to understand the local and national ICT infrastructure to determine the context of the local applications.

The data collection would need to include not only counts of people but also descriptions of their roles. We would need access organizational charts and gather data on the individuals within them, such as job responsibilities, level of education, perceived shortcomings of their education, and career pathways. There would also need to be discussion with HIT leaders of such organizations about their anticipated future needs for IT applications. We would also need to gather data on the types of workers and their desired qualifications.

Of course, gathering research data is not enough. Once we have a good picture of the types of eHealth applications used and workforce to implement required, we will need to develop a plan of action. How can we operationalize this? No single country or region can act alone, nor should they, since standardizing approaches across them will allow achievement of economies of scale as well as sharing of resources and expertise. As such, these must be partnerships under the aegis of international organizations, such as the International Medical Informatics Association and its Working Group on Education. This should lead to partnerships, not only between developed and developing economies, but also among developing economies. An example of the former is the translation of an in-depth on-line introductory course in biomedical informatics from English into Spanish and its delivery to several hundred individuals across Latin America [32]. An instance of the latter, collaboration between two developing economies, is the participation of around 40 professionals from Uruguay in site visits to Argentinean implementations of clinical information systems, and in courses delivered online by Argentinean experts, as one the training strategy for a countrywide element of implementation of clinical information systems in Uruguay [33].

Ultimately, a more comprehensive approach is needed. One promising example is the emergence of a network for the development of the OpenMRS, an open-source EHR that is used widely across Africa [34]. An Implementers Network not only coordinates software development, but also provides communication, training, and professional development. Larger networks whose interests transcend software develop+ ment and focus on larger health issues are essential. An additional emerging network is the institutions funded by the US National Institutes of Health Fogarty International Center, which recently funded eight partnerships in its Informatics Training for Global Health (ITGH, http://www.fic.nih.gov/programs/training_grants/itgh/) Program.

Another activity that is defining workforce and capacity needs, with a focus on local partnerships, is the AMIA Global Partnership Program (GPP, http://www.amia.org/GPP/), funded by the William and Melinda Gates Foundation. The overall aim of the GPP is to develop a project-centric approach to training in the developing world makes sense as a short-term goal, as well as higher-level training (certificate, master's, and PhD) to develop local capacity to continue with training as a middleand long-term goal. Essential for emerging educational programs will be partnering with local universities and other institutions and implementing systems in ways that are compatible with local customs, culture, and health care needs.

The promise of eHealth and mHealth applications to improve global is vast. As these projects develop, leaders will need to be cognizant of the need for a well-trained workforce to lead their implementation. An ideal approach will include needs assessment and education and training opportunities for that workforce. Such an approach should foster the establishment of academic partnerships and centers of excellence in education and research in developing countries for sustainable capacity building, in accordance with local needs.

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STRENGTHENING SIERRA LEONE'S NATIONAL HIS – COLLABORATIVE APPROACH

MAGNUS GBORIE

Sierra Leone may seem like an unlikely place to develop a computerized health information system. The country has emerging from 10 years of civil war (1991 – 2001) that destroyed half of all health facilities and led to the exodus or death of half of the nation's health professionals. As a result, the previous health information system collapsed. In the years since the civil war, a great deal of rebuilding has taken place. However, many of the staff responsible for running the routine health information system at district and national levels has been poorly motivated and poorly trained. All of the limited data available have come from household surveys and reports submitted by outpatient facilities. Hospitals report almost nothing on their services.

To re-build routine monitoring and evaluation, a range of donors and public health programs have introduced a fragmented array of specialized reporting systems. These programs have asked staff at health facilities to complete a large number of often poorly designed data collection forms. This has overwhelmed facility staff, data managers and analysts.

Starting from the level of the facility, information has flowed in only one direction: from facility to higher levels with almost no feedback. Little use has been made of the data at facility level. There has been almost no data coming from hospitals. At district level, data management has been fragmented. Multiple program staff have had responsibility to aggregate facility data, typically without the use of computers. They then have sent paper-based aggregate reports to the capital city, Freetown. This paper-based data management has resulted in transcription and arithmetic errors. And analysts at higher levels have not had access to disaggregated data showing performance of individual facilities.

At national level, the paper reports have been entered into separate electronic databases maintained by diverse programs, the Directorate of Planning and Information, and the National Statistics Office. At national level, analysis and dissemination of routine health statistics has often been neglected as midlevel and senior managers have been pre-occupied with planning, and collection of data through special surveys. The last annual summary of health statistics was published in the early 1990s. This has severely constrained access to data and information. These problems (fragmentation, limited skills and motivation, burdensomedatamanagement) have created avicious circle: incompleteness and poor quality of data have prevented access to useful information which in turn has undermined the motivation at all levels for strengthening the routine health information system.

In recent years the health sector review meetings have been held annually. These demonstrate the limits to the culture of information usage. During the 3 day meetings, presentations and discussions have focussed on plans to rebuild the sector. Only very limited use has been made of health statistics to inform deliberations and document results.

The ministry adopted series of phases to strengthen the national HIS. In The first phase an Assessment was conducted using Health Metrics Network (HMN) tool in 2006. This revealed that a number of stand alone information systems exist within the Ministry, each system supporting a vertical reporting function with little horizontal integration. As a result, essential information is largely unavailable for effective planning, monitoring and evaluation either at district or national level. Human resources are inadequately skilled in all steps of the information cycle (data collection, processing, cleaning, analysis, research etc.) and do not know how to use routine information in planning and performance appraisal. Peripheral staffs are not really aware of what they could do, or should be doing, with data. This lead to the development of the strategic plan, mobilization of \$1 million of initial commitments from the World Bank and refinement of core health indicators.

In 2008, the Ministry of Health and Sanitation elected to launch the implementation process focussing on deployment of an integrated data repository. April to September of 2008 the system was deployed in 4 "pilot districts" (Western Area, Moyamba, Bombali and Kono). In these pilot sites the developers and users resolved the problems with software and hardware and learned how to organize support. The system was gradually expanded so that by February 2009 the DHIS software had been deployed and local area networks installed in all 13 districts. In May and June of 2008 all the District Monitoring and Evaluation Officers who are the backbone of Sierra Leone's routine health information system completed a 3 week course in basic computer skills, operation of DHIS software and presentation/ use of health statistics With funding from the World Bank. In 2009 a major advance, after months of negotiations and lobbying, has been to reach consensus on an integrated form for reporting of reproductive and child health services and commodities. In the coming months, introduction of this new form is to be accompanied by training and job aides to support reporting, data analysis and use of information at the facility level. Once each month each primary care facility submits to district level the paper forms. The integrated RCH form as well as from the HIV services forms are entered into DHIS software at district level by M&E officers. Partnerships of organizations have supported development of Sierra Leone's DHIS. The lead agency has been the Directorate of Planning and Information of the Ministry of Health and Sanitation or DPI for short. The software will automatically generate feedback reports customized for each health facility. The software is being customized to automatically generate standardized reports tailored for each of the major programs, departments and donors. Data are transferred electronically from district to national data repository. For now, internet access is not yet reliable for most districts so data transmission is usually done once each month using USB memory sticks.

Statistics from the DHIS were featured prominently when senior public health officials met in December for the Annual Health Sector Review. The "league table" shown here compared the performance of districts with respect to the completeness of data, quality of data, and coverage with immunization and maternal health services. This presentation was very well received and generated a vigorous discussion about data quality and reasons for variation in coverage with essential services. Review meetings at national and district levels represent an ideal opportunity to re-vitalize the culture of information use.

NEXT STEPS

The training of a core group of Sierra Leonean DHIS experts that include the HMN-funded Sierra Leonean IT Advisor and database manager is to be conducted. These experts will be essential to supporting the on-going customization of the software and assuring the sustainability of the approach in the country. To side-step the issue of who owns the data and to assure rapid, on-site access to the database, plans call for separate servers to be set up near to the program offices as well as in the national statistics office. Work is progressing to re-establish reporting by hospitals. A tremendous amount of work has been completed and an even large number of tasks lie ahead. Facility-level staff needs to be trained in the new forms and in data use. Customized reports need to be developed for various programs and donors and these partners need to be persuaded to buy into the integrated system and drop their old reporting routines.

Hospital reporting needs to be revitalized. We might easily conclude that the challenge is to expand the scope of the system. But this is to overlook the more fundamental challenge which is to foster a culture of information usage. And this cannot be done merely by making the DHIS more complex. the two most fundamental challenges: building capacity and strengthening the demand for information.

When it comes to capacity, three types of human resources are most urgently required: a more qualified and better motivated M&E officer at district level, an IT expert and analysts.

With respect to fostering the demand for information, Staff should be into the habit of presenting and reviewing health statistics:

- annual statistical reports should be published;
- each district, department or program should produce an annual report that provides robust evidence of performance;
- Evidence such as league tables should be presented and vigorously discussed at district and national review meetings.

EHEALTH CAPABILITY BUILDING FOR RURAL HEALTH WORKERS - LESSONS FROM THE TRENCHES

ALVIN MARCELO

Through a grant from IDRC, the University of the Philippines Manila had developed a web-based open source electronic health record for government health centers called CHITS (Community Health Information Tracking System). After the initial successful pilot in two centers, UP Manila began receiving requests for installations in other centers. In addressing this demand, UP Manila learned several lessons in building capability in electronic health records among rural health workers in the Philippines.

The first lesson is that many health workers in developing countries have not used a computer their whole lives. And although an increasing number have cellphones, a significant portion of them still do not use them regularly or with any degree of proficiency. This constrained us to offer a computer literacy program (parts of a computer, turn on/turn off, mouse and keyboard operations, etc) prior to introducing the more complex electronic health record.

The next lesson is that in teaching computer literacy, it is important to provide coping mechanisms to the health workers prior to the hands-on portion of the training program. That is why in the CHITS training program, the health workers do NOT use computers on the first day but rather undergo structured learning exercises first (SLEs – games, workshops, etc) which make them relax and have fun but also introduce the basic concepts of information systems (that it's made up of several interconnected components, that each component influence each other, and that one weak component can result in a non-functional system to list a few). These concepts were found to be important when participants reach the hands-on stage as they lessen the pressure of learning new skills by allowing them to cognitively refer to them repeatedly.

It was also observed that at the frontline, concepts such as epidemiology and national and regional health information systems are difficult for field workers to comprehend. What they do understand however are the required data they they need to collect to adequately take care of their patients, those that are needed for insurance reimbursement, and those that are required by the Department of Health. However, the quality of their data varied. For those which had personal value (patient information needed to take care of the patient and insurance claims data), these tended to have better quality while those which were mandated by higher authorities tend to have lesser guality. These latter data have no immediate and clear value to the field workers (the collectors) and their accuracy, timeliness and completeness are sacrificed. These data are also easy to manipulate and fabricate because there is no quick feedback loop to let the field workers know that the higher levels are able to detect these anomalies.

At the higher levels of the health system, on the other hand, there is a lack of intimacy with the realities of field health workers. Meeting performance targets take precedence over data quality, and in a few instances, there are even paradoxical targets (e.g., contraceptive use must increase as well as immunization rates). Program monitoring systems are designed with great attention to technical detail but without full comprehension of the impact of these tools in the workflow of the data collector (the field worker). In the end, data quality suffer because of the volume of data required for collection from a single health worker in a remote island or barangay by several vertical programs. A seemingly innocent data management practice of merging and consolidating data (on paper) has severe repercussions on data quality. In a facility with five midwives for example, the morale of the diligent data collectors are dashed when their good quality data are invariably mixed with those submitted by colleagues with less impeccable credentials. When personal accountability for data quality are erased after consolidation, lazy and impertinent staff are able to hide behind this smoke screen.

In summary, quality health care is not possible without proper documentation, and proper documentation is a hallmark of quality care. By providing field health workers with (electronic) tools to maintain good documentation, quality care (or lack of) can be measured and monitored. A rural health worker should be empowered with the capacities to document her cases (that is, quality, documented care will be reimbursed; poorly documented care will not be reimbursed). These reasons must be self-serving (at least to the health worker) to ensure data quality as no worker will deliberately trash her data if she needs it to be of good quality for reimbursement. Once these data are collected, the higher levels should leverage these into a data warehouse for analysis and decision making. By following this ground up approach (address the needs of the data collectors first followed by the vertical programs), a robust national health information system can be developed.

eHEALTH CAPACITY DEVELOPMENT IN AFRICA: THE UNIVERSITY OF KWAZULU-NATAL EXPERIENCE. WHAT HAVE WE LEARNED AND WHERE ARE WE GOING?

MAURICE MARS

INTRODUCTION

Sub-Saharan Africa (SSA) faces a disproportionate burden of disease, a shortage of healthcare professionals and limited funds for healthcare provision.¹ Information and communications technologies (ICTs) are seen as a potential means of addressing aspects of the problem by: facilitating and improving timely health data acquisition, interpretation, dissemination and storage; facilitating healthcare delivery through telemedicine; and enabling education over distance. While the potential benefits of ICT in health appear obvious, integration of ICT in healthcare has been slow. There are many reasons for this in SSA, including lack of infrastructure, high connectivity costs, illiteracy and computer illiteracy, restrictive telecommunication legislation, lack of eHealth policy and lack of human capacity in the field of eHealth.

Sub-Saharan Africa did not benefit from the extensive infrastructure deployment that occurred in the developed world during the DOT.COM boom and remains poorly connected. Connectivity is very expensive² and the benefits of the additional submarine cables to the East coast of Africa have yet to be realised. Not surprisingly, Internet penetration in Africa, including Mediterranean Africa is low, 6.8% ³ and in SSA ~ 4%. In South Africa, 49% of people over the age of 16 years do not know what the Internet is.⁴ Probably, as a result of low Internet penetration, only approximately 40 of the 2000 languages of Africa are available on the World Wide Web, further limiting uptake.⁵

It is estimated that about half (96) of the 194 WHO member states have some form of eHealth policy, strategy or roadmap, of which four are African countries.⁶ While there may be political will to introduce eHealth in Africa, there are few people trained in medical informatics or telemedicine in Africa and there are few with experience in implementing ehealth solutions in resource poor settings. This deficit in human capacity has been identified by various funding agencies and professional organisations and endeavours such as the American Medical Informatics Association's Global Partnership Program, the new African Academic Public Health Informatics Alliance and the International Society for Telemedicine and eHealth's basic telemedicine training programme are attempts to address this. There is need to develop and examine different models of eHealth capacity development in the developing world and in sub-Saharan Africa in particular.

This paper reviews an eleven year experience of working towards Medical Informatics capacity development in South Africa and sub-Saharan Africa funded by Fogarty International Training Grants and the NIH and, drawing from this experience, outlines a new approach built on the concept of "developing the capacity to develop capacity".

REVIEW

Phase 1: 1999-2004

The then University of Natal, and Tufts Medical School received a Fogarty Center International Training Grant to develop medical informatics capacity in Africa. The approach taken was the fairly standard model of the day of sending suitable candidates to the USA for training at masters or PhD level and conducting workshops in South Africa to raise awareness in medical informatics.

Workshops were held annually. The first involved bringing 100 people from across Africa to South Africa for a week of medical informatics training and providing computers to those who needed them. While the workshops allowed for exposure to medical informatics and networking, there was insufficient capacity and experience amongst those attending to develop any projects or training on return to their home countries. Two people who attended the weeklong workshop were brought to Durban for a year to take courses in information technology at honours level, not available in their home country.

The return on investment of sending people to the US was limited as the environments to which they returned were not supportive. Several staff from our University were sent to the US to take short courses in medical informatics, with the aim of developing local capacity and ultimately offering a home grown medical informatics programme.

Although not a requirement of the grant coursework programmes in medical informatics at Postgraduate Diploma and Masters level were developed. In South Africa the entry requirement for a Masters is a four year Bachelors degree or an Honours degree, which is a three year Bachelors Degree plus an additional Honours qualification taken over a further year. The process of having the new qualification approved both within the institution and by the various arms of Government took nearly two years. We debated who the target audience should be. It was decided that while we would like to have computer scientists as the core group, we should also include interested health practitioners. This was a compromise and was not the best solution, as the doctors and nurses on the programme obviously did not have the computing skills of the computer science graduates.

The course was run part time over three years, with students having a residential block of three weeks at the start of each semester, with assignments and projects completed from home over the rest of the semester. Faculty from MIT, Harvard and Tufts came to South Africa to teach some of the MI specific modules.

What did we learn from this? Many things: the model of mixing computer scientists and health practitioners in modules on programming and databases was inappropriate and we ended up using the computer science graduates as tutors for the programming and database modules. The needs and expectations of the health professionals were obviously different to those of the computer science graduates. The model of a residential block at the beginning of each semester worked but caused problems for health professionals, who were all in Government employ, as they had difficulty being away from work for this long. We lacked an electronic learning management system and there were problems consolidating all the email and assignments sent by students to the various faculty members. While the health professionals expressed satisfaction with their medical informatics education, their newly gained knowledge was not exploited by their employers.

Phase 2: 2005-2009

The funding in this cycle was to Build Medical Informatics Training in Southern Africa with an emphasis on developing medical informaticians to support research in the region. Building on the initial experience, the curriculum was restructured, setting up a fulltime Masters and Postgraduate Diploma programme for IT graduates and a part-time MPH with specialisation in Medical Informatics for health professionals. The full time masters programme runs over 18 months and consists of a year of coursework followed by a research dissertation worth 50% of the credits for the qualification. The Postgraduate Diploma has a year of coursework, including a small research project. The MPH programme consists of core MPH modules (25%), medical informatics modules (25%) and a research dissertation (50%).

Four separate cohorts of students were enrolled. For the first group, we were only able to recruit two computer science honours graduates from South Africa, because of the small number of honours graduates overall, competition from industry for these graduates and the lack of demonstrable career paths in medical informatics. One of these graduates is now working completing his PhD, teaching on the programme and being mentored to embark on an academic career in medical informatics.

For the second and third groups, we brought 7 students from different parts of Africa to Durban for full-time tuition. While effective, this took them out of their jobs, weakening services in their home areas. Most found being away from home for eighteen months difficult. This model is also not sustainable without external funding.

It was envisaged that the Dept of Computer Science at the University would be partners in the programme, eventually take over administration of the programme, and that students from their honours year programme would enrol in the medical informatics programme. While the Dept of Computer Science provided tuition, restructuring within the University caused a reduction in their own postgraduate programme and ultimately led to their withdrawal from the medical informatics programme.

To address sustainability, a partnership was formed with the School of Information Systems and Technology (IS&T) at the University. One of their programmes produces graduates who have completed either a Bachelors or an Honours degree in Commerce and Information Technology. Nine of their graduates have been enrolled in the fourth medical informatics programme intake. In addition, two of the MI modules have been incorporated into the IS&T Honours programme. Thirty students have taken these modules, exposed them to MI, raised awareness of the MI programme, with eleven of these students applying for entry to the masters programme

The introduction of graduates with both a business manage-

ment and an IT background has led us to develop two streams within the qualification, one with a strong programming element and the other looking at planning, management and implementation of medical informatics programmes.

Phase 3: 2009-2013

During the second phase, the issues around the sustainability of bringing students from other African countries to Durban, led to the obvious realisation that MI training should be available to students in their home country. However, with the shortage of academic capacity in MI in Africa new model is required. The model is based on initial sharing of teaching and curricula, thereby enabling partner institutions to "develop the capacity to develop capacity", with an end goal of forming sustainable academic medical informatics departments or units at partner institutions. It is acknowledged from the outset, that institutions would have different skill sets, different existing computing modules that might be incorporated into the programme and that academic bureaucracy will differ. As a principle, any programme offered must be relevant and appropriate to the medical informatics needs of the country.

As a starting point, the existing postgraduate programmes in MI at UKZ-N will be offered in a collaborative manner to partner institutions. This will be achieved by ICT based distance education using desktop videoconferencing, supported by a learning management system for the distribution of materials, submission of assignments, student communication and student administration.

Staff at partner institutions will be expected to act as local mentors and if necessary take modules themselves to build local teaching capacity. For MPH programmes, MI modules will be added to the existing programmes to develop a specialist MI stream or for elective purposes, with the teaching coming initially from UKZ-N.

The ICT distance learning model is based on experience of teaching other courses by interactive distance learning in Africa. We make extensive use of ISDN and IP based videoconferencing at out medical school, with 1,298 hours of interactive teaching broadcast in 2008. Videoconferencing into Africa is expensive and we have used other solutions ranging from an open source low bandwidth desktop videoconferencing programme DimDim, Skype with with PowerPoint presentations made available in advance on an ftp site or on a

learning management system, and at times combinations of these used concurrently witht different sites. We now make extensive use of a learning management system to distribute reading materials, set, receive and mark assignments and hold discussion forums.

If successful, the first groups of institutions will then be in a position to replicate the model in their region, so as to achieve the ultimate goal, which is the development of a consortium of African Universities offering MI programmes of similar standard, with shared teaching. We have partnered with Universidado Eduardo Mondlane in Mozambique, Makarere University in Uganda, the University of Zimbabwe, and University of the Witwatersrand in South Africa.

DISCUSSION

The experience gained and the new project with other African Universities addresses only part of the far larger problem of capacity development in medical informatics. In discussion with colleagues developing and implementing medical informatics solutions in different countries in sub-Saharan Africa, several other important issues relating to capacity development have emerged that need to be addressed.

Medical informatics is not seen as a career path. There is need to involve local and national Ministries of Health in medical informatics training programmes so that research projects are relevant and add value to the Ministries of Health. At the same time advocacy is needed to develop posts and career paths in MI within ministries.

Medical informatics training is needed for all levels of health workers. This is based on the observation of the lack of a "culture of data acquisition" in many health systems around Africa. Health workers responsible for data gathering and capture do not necessarily understand why they have to capture data and why it must be captured accurately. Many also have limited understanding of data interpretation, down to the level of not being able to read a graph or interpret tables. Training needs to address data capture, data interpretation, system maintenance, system development, research, planning and management.

There is often limited capacity and experience within governments in developing countries to formulate appropriate

MI policy and strategies within the constraints of small budgets. Specific short courses need to be developed to address this.

CONCLUSIONS

The problems of capacity development for medical informatics will require many different interventions. The development of a consortium of African Universities sharing curricula and teaching through distance education is one possible solution.

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Charu C. Garg, Ph.D. is a Senior Economist (Health) at HDNHE at World Bank. She leads the Bill and Melinda Gates funded project on National Health Accounts (NHA) institutionalization. She is a health financing expert and has worked globally with wide experience in South Asia, Pacific, Central Asia, Africa and Eastern Europe. Prior to joining the Bank, Dr. Garg has over 5 years of experience in Health System Financing department of the World Health Organization and about 18 years of research, teaching and consulting experience with several international organizations in India and United States. She was a post doctoral Takemi fellow at the Harvard School of Public Health. She has worked extensively on issues related to health insurance, equity aspects of health financing and delivery, impoverishment and catastrophic payments, out of pocket payments, household surveys, foreign aid, financing for specific diseases and National Health Accounts. She has published in peer reviewed journals and presented widely.



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My name is Dr. Magnus Ken Gborie, male by sex, born on the 14th of August in 1959, in Sierra Leone. I am currently resident at 27 Femi Turner Drive, Godrich, Freetown, Sierra Leone. I am married with a son.

I am a medical doctor and a public Health specialist by profession. I obtained my Bachelor in Medicine and Bachelor in Surgery (MB,BS) degree at Shangai Medical University, China, in 1989. In 1993 I obtained a Master of Science degree in Public Health in developing countries at the School of Hygiene and Tropical Medicine of the University of London, UK. In 1995, I obtained a certificate in Management of Health Services Projects and Programmes at the Clark Atlanta University – Atlanta, Georgia – USA. I have subsequently attended several certificate courses and seminars on health systems management including health information management systems and on health systems strengthening. In 2009 I obtained a Master of Business Administration (MBA) executive option degree at the Njala University, Sierra Leone.

I am currently the director of Planning and Information of the Ministry of Health and Sanitation. As Director, I coordinate efficient planning of all health activities both at National and District levels and facilitate the establishment of effective health information systems to monitoring progress and evaluate impact of health activities. From April 2004 to year 2008, I was Programme Manager of the Maternal and Child Health/ Expanded Programme on Immunization (MCH/EPI) Programme. As Programme Manager, I was responsible for the design, monitoring of implementation and evaluation of programme policies; and the assurance of quality and continuity of the programme. From March 2003 to April 2004 I was Programme Manager, of the Disease Prevention and Control programme. In that capacity, I planned in close collaboration with the National Surveillance Coordinator, monitor implementation and evaluated policies set to strengthen national capacity to detect, investigate and monitor communicable diseases; as well as their causes; and responded appropriately to public health problems as they were identified. My specific roles included public health infrastructure and capacity building, disease prevention and control, operational research and information sharing.

From January 1995 to February 2003, I served as Programme Manager of the National Leprosy and Tuberculosis Control Programme. As Manager, I was responsible for the design, monitoring of implementation and evaluation of programme policies; and the assurance of quality and continuity of the programme. My specific roles included epidemiological surveillance, operations, and human resource management.

From June 1994 – December 1994, I served as District Medical Officer (DMO) – Bo District, one of the 13 districts in Sierra Leone. As DMO, I was head of the District Health Planning Supervisory and Administrative Team. I directed health planning, implementation and evaluation within the district. I represented the Principal Medical Officer in the district on all matters relating to Public Health, and in addition participated in health planning at provincial level. From 1992 to June 1994 I was Medical Officer in charge of Sexually Transmitted Infections Unit, National AIDS Control Programme.

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Dr. Hersh is also involved in global efforts to expand informatics capacity through education. He is Chair of the International Medical Informatics Association Education Working Group and has ongoing educational project collaborations in Argentina, Singapore, Egypt, and Zimbabwe. He is also Chair of the Training Approaches and Contents Committee of the AMIA Global Partnership Program (GPP).

Dr. Hersh has won numerous awards for his educational innovations. These include the OHSU Faculty Senate Distinguished Faculty Award for outstanding teaching in 2007 and the 2008 AMIA Donald A.B. Lindberg Award for Innovation in Informatics.

Dr. Hersh has also made many contributions in research. His most recent work has focused on the quantity and characteristics of the workforce needed to implement health information technology, especially in clinical settings. Dr. Hersh is also active in clinical and translational research informatics. He serves as Director of the Biomedical Informatics Program of the Oregon Clinical & Translational Research Institute (OCTRI, www.octri.org) and was Chair of the National Informatics Steering Committee of the Clinical & Translational Science Award (CTSA) program of the National Institutes of Health from 2006-2008. His research originally focused in the area of information retrieval, where he has authored over 100 scientific papers as well as the book, Information Retrieval: A Health and Biomedical Perspective (Springer, 2009), now in its third edition and which has an associated Web site, www.irbook.info.

More information about Dr. Hersh can be found on his Web site at www.billhersh.info. He also maintains the Informatics Professor blog at informaticsprofessor.blogspot.com.

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Mars serves on the joint WHO Global Observatory for eHealth and U21 Global eHealth Policy Committee, the African Academic Public Health Informatics Alliance, the Global Partnership Program Governance and Structure workgroup and chairs the International Society for Telemedicine and eHealth's Education Committee. He is on the Editorial Board of the Telemedicine and eHealth Journal and is an active member of the International Society of Telemedicine and eHealth, the American Telemedicine Association and the Canadian Society for TeleHealth. He has been invited to present aspects of his work at meetings in Africa of the Commonweatth Secretariat, the United Nations Office of Outer Space Affairs, the United Nations Economic and Social Council and he participated in the Policy Meeting at the 2008 Bellagio Meeting, Making the eHealth Connection, for which he wrote a discussion paper, "eHealth Policy- the Road to the New Digital Divide." Mars holds international and national grants for eHealth research and capacity development and his research group's current activities include, ethical and legal issues relating to telemedicine in the developing world, tele-education solutions for the developing world and developing eHealth Economic models for the developing world. He has over a hundred peer reviewed journal publications and has written chapters in several books.

An international field hockey player while a student he has remained active in the sport as a national selector. He still paddles the 120 km Dusi Canoe Marathon and serves on the Canoeing South Africa Executive Committee as the Medical Advisor.



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Prince Mahidol Award Conference 2010

PARALLEL SESSION 2.3:

UNIVERSAL ACCESS TO HEALTH AND HEALTH SERVICES:

ESSENTIAL INFORMATION TO TRACK PROGRESS AND SUPPORT MANAGEMENT FROM MEASURING INPUTS TO MEASURING IMPACT?

Global Health Information Forum

EXPERIENCES OF USING HEALTH INSURANCE CLAIMS DATABASE TO SUPPORT PURCHASING DECISIONS – ESTONIAN CASE

HANNES DANILOV

Estonia is small country with population 1,4 million people. Financing of health care is social health insurance based (since 1992), entitlement relies on employment; children and retired people are insured on solidarity bases. Population coverage is about 95%.

Estonian Health Insurance Fund (EHIF), established in 2001, is semipublic legal entity. Estonia has a single purchaser system where EHIF is all publicly funded purchasing primary care, acute care and nursing care services for insured population.

All residents in Estonia have unified ID number which is also used as insurance entitlement basis by EHIF. All medical claims are personalized, which creates possibility to link all utilized health services with by consumer and his or her characteristics (e.g. sex and age). At the same time EHIF has information about service provider (institution, doctor) and provided services at patient level. All information that is available through other registers is not kept in EHIF database but is accessible in real time by using persons ID (e.g. address is coming from Population Register).

Within last 8 years EHIF has been developing electronic data transmission system and all data between EHIF and provider (physicians, all acute and nursing care providers and drug stores) is processed through electronic channels.

EHIF budget is allocated capitation basis between 4 regional departments of EHIF to ensure equal revenue base for different regions. However this will not always guarantee equal access to different interventions by different regions and population groups. EHIF's personalized database is a valuable source for analyzing access to care to support better purchasing decisions when EHIF is negotiating next period contract conditions by providers.

Personalized claims data is also valuable precondition for development of family physicians "quality bonus system", which Is Estonian version of disease management program. Patients with chronic diseases like hypertension, diabetes, and ischemia are treated and monitored regularly on ID bases by EHIF and performance of each family physician is assessed yearly.

In additions EHIF database is a good source of information for broader analysis and enables to ling different registers and statistical information available, e.g. region socioeconomic characteristics.

MONITORING EFFECTIVENESS OF UNIVERSAL COVERAGE IN THAILAND

SUPON LIMWATTANANON ^{1, 2} VIROJ TANGCHAROENSATHIEN ²

This paper draws evidence from historical data on health outcomes, outputs, and inputs to a better understanding on Thailand's achievement in universal health coverage.

1. ACHIEVEMENT IN POPULATION HEALTH

International evidence indicates Thailand stands at the top league among 30 low- and middle-income countries (LMICs) with a rapid reduction in child mortality during the last two decades (Rohde et al., 2008). Our analysis of the link between under-five mortality and health expenditure in LMICs reveals Thailand is one of the 'Good Health at Low Cost' countries (Figure 1).



FIGURE 1. UNDER-FIVE MORTALITY AND PER CAPITA HEALTH EXPENDITURE IN LMICS, 2000-2005 **SOURCE:** ANALYSIS OF WORLD HEALTH STATISTICS

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2. DEVELOPMENT IN HEALTH SYSTEMS

When the Ministry of Public Health of Thailand was established in 1942, only 15 provincial hospitals outside Bangkok existed. Twenty years later, Thailand had the first five-year National Health Plan (NHP) in 1962. Over four and a half decades (1962-2007), nine NHPs have implemented consecutive development in health systems. The first five NHPs laid a solid foundation through an expansion of public infrastructure (provincial hospitals in NHPs 1-3 and district hospitals in NHPs 4-5) and human resources (rural mandatory service for new doctors in NHP 3 and production of technical nurses in NHP 5). The second phase evolved around an expansion of health insurance using innovative financing mechanisms, namely the Social Security Scheme (SSS) for formal private sector employees in 1991 and the Universal Coverage Scheme (UCS) for the rest of population in 2001. This recent development is a long march after piecemeal, targeting approaches by the Low-Income Card Scheme (LICS) for the poor in 1975 and later expanded to all children, the elderly and disabled; and the Civil Servant Medical Benefit Scheme (CSMBS) for government employees, government pensioners and their dependants in 1980 (Tangcharoensathien et al., 2009).

2.1 HEALTH INFRASTRUCTURE AND HUMAN RESOURCES

Public hospital coverage at the district level began in 1977 (Figure 2). The next two decades experienced a continual two-digit growth of district hospitals (mostly 10-60 beds) with a peak of 27 hospitals per year during 1982-1991. This historical moment is the foundation for future scaling up in the geographical coverage of health services after the provincial hospitals were saturated in all provincial cities and the rural health service was mandated to new medical graduates in the third NHP in 1972. Improvement in the population-nurse ratio was boosted by the first batch of technical nurses (with plans to upgrade to professional nurses) in 1982, the same year the Expanded Program of Immunization (EPI) was first implemented. The 1997 Asian Economic Crisis stagnated the boom of private hospitals and bed density after SSS, a social health insurance for formal private employees was first implemented in 1991.



FIGURE 2. HEALTH INFRASTRUCTURE AND HUMAN RESOURCE TRENDS IN THAILAND, 1962-2007 SOURCE: AUTHOR ANALYSIS OF HEALTH RESOURCE SURVEYS (VARIOUS YEARS)

2.2 HEALTH INSURANCE AND FINANCING

Thailand achieved a universal coverage of health insurance in 2001. Our analysis found the uninsured population dropped substantially from 67% in 1991 (the first year of social health insurance) and 29% in 2001 to less than 4% in 2007.

Over the last decade, Thailand has maintained health expenditure at a relatively consistent ratio at 3.5-4% of total economy (measured by GPD) despite during the Asian Economic Crisis in 1997 (Figure 3). Health spending shared by households shrank from 45% in 1994 to 20% in 2007 with an increasing trend in the government expenditure. Decreasing poor-rich gaps in catastrophic expenditure and out-of-pocket payment for health were observed, largely due to a reduced financial burden to the poor households.



FIGURE 3. HEALTH EXPENDITURE TRENDS IN THAILAND, 1994-2007

SOURCE: NATIONAL HEALTH ACCOUNTS; ANALYSIS OF SOCIO-ECONOMIC SURVEYS (VARIOUS YEARS)

3. LINKING AN IMPROVEMENT IN HEALTH OUTCOMES TO INPUTS

This paper teases out relationships between a decreasing trend in child mortality and improved density of health resources during 1970-2007 using a time-series analysis taking account of the first-order serial correlation. Our analysis found statistically significant effects of a reduction in the population ratios to doctor, nurse, and hospital bed on the decline in U5MR, independent of the growth in national income per capita (Figure 4). The U5MR would reduce by 0.3, 1.2, and 3.8 per 1,000 live births, respectively as the ratios to doctor, nurse, and bed reduced by 100 people.



FIGURE 4. UNDER-FIVE MORTALITY AND POPULATION-DOCTOR, -NURSE, AND -BED RATIOS, 1970-2007

4. HEALTH EQUITY

Thailand achieves an improvement not only in an overall level of health outcomes but also in the distribution of key health services provided by the public sector during the UC era. Data in 2006 reveal basic immunization equally distributed across economic gradients of target children, whereby concentration indices (CI) for polio, BCG, DPT, and MMR vaccines are very close zero (Limwattananon et al., 2010). This is likely a result of a very high overall coverage beyond the 80% desired threshold (91.5%, 98.0%, 91.4%, and 91.4%, respectively). Historical data of EPI reveal that within the 10 years of NHPs 5 and 6, the DPT coverage rapidly increased (on average 6.7% annually) from 21% in 1982 (the first EPI year) to 73% in 1987 and 91% in 1992. Our analysis found improved population densities of nurses and district hospitals are statistically associated with growth in the DPT coverage over the last 25 years.

For curative care services, the utilization in district health facilities was consistently pro-poor for both ambulatory visits (CI -0.27 to -0.38 for health centers and -0.25 to -0.32 for district hospitals) and hospitalization (CI -0.24 to -0.32 for district hospitals), whereas that in private clinics and hospitals was pro-rich (CI 0.25 to 0.53) over the years 2001-2007 (Prakongsai et al., 2009).

The health equity goal is still unachieved with respect to distribution gap between economically better-off and worse-off geographical areas. This is obvious in the case of health resource density between Bangkok (the richest urban) and the poorest Northeast region. The Bangkok-Northeast ratio in population per doctor decreased substantially during the rural health development program in NHP 4-5, and then died down to the ratio of approximately 8; whereas the gaps in nurse-and in bed-density are relatively stable at a ratio of 4 over the 1995-2007 period (Figure 5).



FIGURE 5. POPULATION RATIO TO DOCTORS, NURSES AND HOSPITAL BEDS IN BANGKOK AND IN NORTHEAST REGION, 1995-2007 Apart from the per capita income, our decomposition analysis found the geographical inequity between urban-rural areas was the most important factor, contributing to almost 11% of the inequities in weight for age and in height for age of the under-five children.

The above finding prompts further policy attention to the sub-national information for health systems monitoring and evaluation. This paper will explore the case of provincial variations in health and related factors.

5. PROVINCIAL VARIATIONS IN HEALTH OUTCOMES AND INPUTS

Two variables, gross provincial product - GPP (in Baht per capita) and poverty head count ratio (% of total population) were used to capture the underlying economic variation across 76 provinces of Thailand. The former variable relies on administrative reports, whereas the latter is obtained from a small-area estimation poverty map based on household surveys (in our case, Socio-Economic Surveys - SES). Our analysis found the logarithmic GPP correlates moderately with the poverty head count ratio (correlation coefficient, r = -0.4).

The direction of the bivariate association between U5MR and provincial economic well-being is not unexpected: an inverse and non-linear relationship for the GPP measure and a positive and linear relationship for the poverty head count (Figure 6). Our analysis found magnitude of the relationship with GPP (R2 = 0.064) is a little larger than with poverty (R2 = 0.036).







FIGURE 6. PROVINCIAL ECONOMIC WELL-BEING MEASURED BY GROSS PROVINCIAL PRODUCT (GPP IN BAHT) (LEFT PANEL) AND POVERTY HEAD COUNT RATIO (%) (RIGHT PANEL) AND ITS RELATIONSHIP WITH U5MR, 2004 SOURCE: AUTHOR ANALYSIS OF DATA FROM NESDB AND VITAL STATISTICS

Provinces also vary widely with respect to health resource density. The number of doctors, nurses, and beds per 100,000 population in an inverse scale, each can explain the provincial variation in U5MR (R2 = 0.089-0.136) better than the measures of provincial economy (Figure 7).



FIGURE 7. PROVINCIAL VARIATIONS IN HOSPITAL BEDS, DOCTORS, AND NURSES PER 100,000 POPULATION AND RELATIONSHIP WITH U5MR, 2004 SOURCE: AUTHOR ANALYSIS OF DATA FROM HEALTH RESOURCE SURVEYS AND VITAL STATISTICS

The density of hospital beds, doctors, and nurses among 76 provinces are correlated to each other very well (r = 0.82-0.86). This hints that growth in health workers would follow growth in health infrastructure. The policy message is to mitigate the shortage of the health workers, and the priority should be to reduce the geographical gap in the infrastructure. In addition, the retention issue should be balanced against the expanded production of new health workers.

6. READILY AVAILABLE DATA SOURCES

To realize an improved health and its link to the universal access to health services would be difficult if a country does not have readily available data. Thailand is fortunate to have complementary sources of data for generating such evidence. While nationally representative household surveys provide most information on the demand-side characteristics, health service utilization and expenditures, facility-based administrative reports like the Health Resource Surveys contain lot of data on supply-side variables. We have shared in detail Thailand's lessons on health information systems for equity monitoring elsewhere (Tangcharoensathien et al., 2007). The table below summarizes features of each data source we used for the above analysis.

Types of databases	Time periods	Variables of interest
A. Household surveys		
1. Socio-Economic	1957-1986 (q 5 yr)	Consumption and non-consumption expenditures
Surveys (SES)	1988-2006 (q 2 yr)	Earned/unearned money and in-kind incomes
(n ~ 20-30K)	2007 onward (q 1 yr)	
2. Health and Welfare	1974-1978 (q 1 yr)	Non-hospitalized and hospitalized illnesses
Surveys (HWS)	1981-2001 (q 5 yr)	Health care choices
(n ~ 20-30K)	2003-2007 (q 1 yr)	Out-of-pocket health payment
	2009 onward (q 2 yr)	
Panel SES	2005, 06, and 07	Incomplete health module in 2005-07
(n~6K)	2010	Revised health module in 2010 (unmet need, utilization,
		OOP payment, coping and economic impact)
4. Surveys of	1942-1952	Birth, death, and migration
Population Change	1965-2005	
(SPC)	(Inter-census, q 10 yr)	
5. Population and	1909-1929	No data on household expenditure and income
housing census	1937-1947	
	1960-2010	
	(q 10 yr)	
B. Administrative reports		
1. Civil Registration	1957-2007	Population and vital statistics
2. Health Resource	1962-2007	Number and type of hospitals, beds, doctors, nurses, and
Surveys		others
3. National Health	1994-2007	Health spending by functions, agents, and sources
Accounts		

TABLE 1. DATA SOURCES FOR GENERATING EVIDENCE ON IMPROVED HEALTH AND UNIVERSAL ACCESS TO HEALTH SERVICES, THAILAND

In this paper, we used Socio-Economic Surveys (SES) to estimate the magnitude of household payment for health and evaluate the equity in health financing. Health and Welfare Surveys (HWS) were used for monitoring health insurance coverage and equity in health service utilization. These two regular surveys, however, usually lack health outcome variables that require physiological measures, which are "equity in child malnutrition", analyzed using the UNICEF-sponsored Multiindicator Cluster Survey (MICS). We used a lengthy (45-year) time-series on the number of population and health resources from administrative reports to track progress in health infrastructure and human resources at the national level and assess the provincial variations.

7. CONCLUSIONS

Our paper sheds light on the potential use of regularly collected/ reported data for generating evidence on the progress of Thailand health systems. We exploited a lengthy time series of national datasets to explain the causal link between improved health outcomes and access to resource inputs. Sub-national data on provincial variations can be used to monitor geographical inequity in health resource distribution. To have the complete demand- and supply-side variables, linking the data between regular household surveys and routine administrative reports can be both a challenging and an opportunity issue.

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CATASTROPHIC IMPACT OF OUT-OF-POCKET PAYMENTS FOR HEALTH CARE IN ASIA

JUI-FEN RACHEL LU CHANG GUNG UNIVERSITY, TAIWAN

One of the key objectives of introducing a compulsory health insurance or directly providing comprehensive services is to provide its citizens regardless of socioeconomic status with risk protection against unexpected catastrophic expenditures in the face of illness. Catastrophic health payment, defined as payments in excess of a substantial fraction of household available resources, may imply that households are forced to divert available resources to health care, therefore sacrificing alternative uses of resources. Hence, when OOP payment represents a significant share of financial sources for health care, one should be particularly concerned about the distribution of such payments and the potential impact of the adverse effects across households of differing economic levels.

Threshold analysis, proposed by Wagstaff and van Doorslaer (2003), has been widely applied to assess the magnitude and the distribution of the household direct OOP payment across different household economic levels in various countries. Adopting the methodology, Equitap examined the burden of direct OOP payment in the Asia-Pacific region (Van Doorslaer, O'Donnell, Rannan-Eliya, et al., 2007). The empirical evidence shows that countries which have constrained the OOP share of health financing tend to have lower incidence of catastrophic payment. In most low/middle-income countries, the better-off are more likely to devote a large fraction of total household resources to health care, which may reflect the inability of the poorest of the poor to consume health care services and possibly the protection of the poor from user charges offered in some countries. The change in the incidence and distribution of catastrophic health payment before and after the introduction of the National Health Insurance programs in South Korea and Taiwan, two advanced Asian economies which achieved universal coverage through mandatory social insurance schemes in 1989 and 1995 respectively, were further examined. In spite of South Korea and Taiwan's attempts to achieve the goal of financial risk protection for more than a decade, past research has demonstrated that household out-of-pocket payment still accounts for more than one-third of total health expenditures in both countries.

The analyses were performed on household expenditure surveys composed of national representative samples and 10%, 15%, 25% were chosen as the threshold levels of incurring catastrophic payment. The empirical results show that the headcount of catastrophic payment did decrease when NHI was first introduced, but it seems to level off as years went by. Korea in general demonstrated a higher headcount of catastrophic payment at any given threshold level than Taiwan. However, the catastrophic payment incurred tends to concentrate more on the poor in Taiwan than in Korea. The results are further examined along with use rates to dissect the differences in pro-poor tendency in incurring catastrophic payment between Korea and Taiwan, and how this relates to the design of the insurance schemes. The experience of South Korea and Taiwan will provide valuable evidence to countries that seek to expand insurance coverage, and on what deficiencies may arise.

THE MEXICAN ELECTRONIC CLINICAL RECORD PROJECT

GIOTA PANOPOULOU

The efforts of the Mexican government to create a National System of Electronic Clinical Record (ECR) under the leadership of the Ministry of Health (MOH) date back to 2003.¹ The objective of the project is to create an electronic system in the health sector that will establish basic standards at a national level for the collection and use of patient data under conditions of confidentiality and authorized access. As such, the project does not consist in creating a common software to be distributed to all health related institutions in Mexico, but it rather aims at developing a common platform that will allow communication between the various information systems established in the country.

The Mexican health system is characterized by the co-existence of various sub-systems.² In some cases, health services are offered as part of a compulsory social security benefit package which also includes pensions, disability benefits, day-care, etcT. This is the case of private employees and their families who are affiliated to the Mexican Institute of Social Security (IMSS-Instituto Mexicano de Seguro Social) and public employees and their families who are affiliated to the Institute of Security and Social Services for Government Workers (ISSSTE-Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado). Apart from these two major social security schemes, there are other smaller institutions that serve employees of the navy (SEMAR), the National Defence Ministry (SEDENA), the government-owned oil monopoly company (PEMEX), and the state governments (State-ISSSTE). Each one of these schemes have their own network of health care providers. According to administrative data in 2008, 46% (48.9 million) of the Mexican population was insured by IMSS and 10% (10.9 million) by ISSSTE. The smaller social security schemes covered approximately 2% of the population, while another 2% had some type of private insurance. Before 2003, the rest of the population received health care services at

¹ Secretaría de Salud (2009), Acciones y avances en torno al diseño, desarrollo e implementación del Sistema Nacional de Expediente Clínico Electrónico, Dirección General de Información en Salud, Subsecretaría de Innovación y Calidad, Noviembre 2009.

² For a detailed description of the Mexican health system see, OECD (2005), OECD Reviews of Health Systems Mexico, OECD: Paris.

facilities of the MOH and the state governments (State Health Services).³ Starting January 2004, a new scheme, the Social Protection System in Health was introduced, commonly known as Popular Health Insurance (*Seguro Popular de Salud*). Individuals who are not covered by the social security schemes available in the country are expected to affiliate to this scheme. The scheme offers a well-defined benefit package and medicine at facilities of the MOH and the state governments. End of 2008, 26% (27.1 million) of the Mexican population was affiliated to Popular Health Insurance and there was approximately 14% (15.4 million) who was not insured by any of the available schemes. Universal coverage is expected to be attained by the first semester of 2011 when all uninsured individuals will be covered by Popular Health Insurance.

Having said this, there are various estimates of the number of individuals and families covered by Mexican social security institutions. Census 2005 data suggest that 32% of the Mexican population is insured by IMSS and 6% by ISSSTE, which brings down the number of affiliates of the two major social security schemes to 34 million and 6 million, respectively. This eventually more than doubles the number of individuals still to be covered by Popular Health Insurance (33% of the population or 35 million). The main reason explaining differences in the number of affiliates to social security between administrative and survey data is related to the method used for estimating the number of dependents of each private/public employee. For example, IMSS does not have a roster of affiliates, but only registers those actually paying a contribution (18.7 million in 2008) or having registered with a health unit (43 million in 2008).⁴ IMSS estimates the population it covers by applying a dependents' ratio to the number of contributing individuals. These data are considered to be overestimates, both because of the application of a high dependency ratio, as well as because of double counting within institutions and multiple affiliation between institutions. A similar situation applies to ISSSTE.

³ United States of Mexico is a federation of 31 states and the Federal District. Health care services are decentralized at the state level and each state has each own State Health Services.

⁴ Interview with Francisco San Martin Roman, Head of Division of Support to Affiliation Processes, Mexican Institute of Social Security, December 16th, 2009. The data base of contributors is called SINDO (*Sistema Nacional de Derechos y Obligaciones*), while the data base for those registered at health facilities is called Acceder. Acceder data bases are local. For data see *Memoria Estadística*, www.imss.gob.mx

One of the main benefits of the ECR project is related to the decrease of this type of data discrepancies given that will allow for a more precise identification of affiliates and will facilitate the comparison among data bases of different institutions that nowadays does not necessarily occur.

Currently, health sector institutions work both in coordination and individually in developing ECR systems. At a sector level, all health institutions participate in the elaboration of an Official Regulation that defines the way that the National System of Electronic Clinical Record is expected to work. This regulation, known as *Norma 24*, establishes, among other things, the minimum level of data information and quality standards included in an ECR, as well as the characteristics that all institutional ECR systems should have in order to be able to exchange data among different bases. The development of *Norma 24* started in 2007 and since that period has gone through a process of consultation and authorization by different levels of the central government and the general public. It is expected to come into effect beginning of 2010.

At an individual level, the two major social security institutions, IMSS and ISSSTE, are both working on their own ECR systems. In particular, in the last 6 years, starting 2003, IMSS has developed a series of data bases related to clinical records.⁵ There are four types of systems actually operating, some to a greater and other to a lesser extent. The first and most widely used system is the Information System for Family Medicine (SIMF-Sistema de Información de Medicina Familiar). This is a system designed to work as a clinical record for consultations provided by family doctors in IMSS and is installed in 1,206 family medicine centers from a total of 1,216 (the ten remaining centers being in remote areas of the country). The second system is called Information System of External Hospital Consultations (SICEH-Sistema de Information de Consulta Externa Hospitalaria). It is similar to SIMF but it involves consultations with specialists. The other two systems available cover hospitalizations; Information System for Hospitals (SINHOS-Sistema de Información Hospitalaria) and IMSS VistA. The later was based on a system available in US Veteran Affairs hospitals and was donated to IMSS a decade ago; however nowadays is rarely used. SINHOS is installed in approximately 80 from 226 IMSS second-and third-level

⁵ Interview with Genaro Vega, Advisor to the Medical Services Directorate, Mexican Institute of Social Security, December 8th, 2009.

hospitals, while SICEH in another 80 hospitals. As it is evident from the number of facilities using the various information systems available, the greatest needs are observed at the hospital level. In addition it is worth mentioning that the way the systems are designed does not allow any communication/data transferring among them.

With these needs in mind, IMSS is developing what is called a New ECR System (*Nuevo Expediente Clinico Electrónico*). The institution has passed the initial stages of research and planning and it has developed roughly 70 percent of the new product which is expected to be launched in March 2010. The new product will constitute a unique clinical record for each IMSS patient but with various modules covering family medicine consultations, external hospital consultations with specialists, hospitalizations, clinical exams, results, prescriptions, etc. The implementation of the new system will start from hospital units that currently have no information systems at all.

On the same lines as IMSS, ISSSTE has an ECR system called ISSSTEMED. Starting December 2009, Version 4 of this electronic information system has begun to operate in health facilities in 19 of the 31 states of Mexico. This first face is expected to last until May 2010 and by that time the system will be operable in 354 facilities of first-, second- and third- level of a total of 680 facilities of the institute. For this to materialize, 1,800 professionals (doctors, nurses and administrative personnel) have received technical training. States and facilities have been selected on the basis of the technical infrastructure they have in their disposal related to PC infrastructure and telecommunications, as well as their willingness to participate in this first stage of the project.

As mentioned above the National System of Electronic Clinical Record is expected to allow the interoperability of the diverse sub-systems of the health sector. Following the publication of *Norma 24*, public institutions will have a transition period of 6-12 months to implement the official regulation.⁶ Eventually, the system envisages that private sector providers will also join, but at an initial stage their participation is not compulsory. As already discussed, IMSS and ISSSTE are in the process of implementing their own ECR systems with software developed

⁶ Interview with Luis Priego, Deputy Director of Management and Coordination, General Directorate of Information in Health, Ministry of Health, December 15th, 2009.

by each institution. At the level of the MOH and the State Health Services, authorities do not necessarily plan to develop their own products but rather use bidding processes in order to acquire the necessary software.

The system will have two levels of operation, the central/federal level and the local level. The central level refers to exchange of information between the central institutions (IMSS, ISSSTE, MOH, State Health Services), while the local level refers to exchange of information between local providers (hospitals, health care centers, etc.). A pilot took place recently where information was exchanged between different ECR systems of the State Health Services of Sinaloa and Nuevo León, and ISSSTE. The main objective of the pilot was to show that this exchange was technically viable. It is expected that the full implementation of the National System of Electronic Clinical Record will take place during the period 2010-2013 and will have a cost of 140 million dollars. These resources will allow for the connectivity of all health institutions under the supervision of the MOH. Among the major benefits stemming from the implementation of this new system are the following:

- provide better quality of health care services through the use of a system that does not exclusively rely on the memory of the patient or paper records that are not easily transferable,
- reduce time and monetary costs of health operations by avoiding duplication of medical interventions or unnecessary interventions,
- improve medical practice by optimization of available information, use of reference systems and application of medical guidelines,
- produce savings of public resources in terms of reduced social security contributions made by the government in its role as an employer due to the existence of a unique registry of affiliates,
- allow for early detection of emerging diseases (see for example the virus of Influenza A H1N1)
- enhance the development of public policy through higher availability of systematic, reliable and updated information.



HANNES DANILOV

CHAIRMAN OF MANAGEMENT BOARD ESTONIAN HEALTH INSURANCE FUND

I graduated University of Tartu as chemist- teacher of chemistry at 1977.

Until nineties I used to be teacher and principal of high school. In nineties I used to be governor in West- Estonian County and permanent undersecretary in Ministry of Social Affairs of Estonia.

Since 2002 I work for Estonian Health Insurance Fund as chairman of management board.

I have had some further trainings in Harvard University and World Bank :

- Leaders in development 2000
- Getting health reform right 2005
- Improving the quality of healtH services 2008

I am 55 years old. I am married and we have three children.



SUPON LIMWATTANANON

ASSOCIATE PROFESSOR KHON KAEN UNIVERSITY THAILAND

Supon Limwattananon is an Associate Professor and Director of the doctoral degree program in Pharmacy and Health Systems at Khon Kaen University. He is also a part-time senior researcher at the Ministry of Public Health International Health Policy Program (IHPP), Thailand. He earned Bachelor of Pharmacy from Chulalongkorn University in 1982, Master in Primary Health Care Management from ASEAN Institute for Health Development in 1991, and Doctor of Philosophy in Social and Administrative Pharmacy from University of Minnesota in 2000. He was a Fulbright Scholar during 1993-1996 and received the US Health Care Financing Administration Dissertation Award in 2000. His expertise is in the areas of health economics and micro-econometrics.



J. RACHEL LU

PROFESSOR AND ASSOCIATE DEAN CHANG GUNG UNIVERSITY TAIWAN

Jui-fen Rachel Lu, Sc.D., is a Professor and Associate Dean in the Department of Health Care Management, College of Management, at Chang Gung University, where she has served as a department chair from 2000 to 2004 and teaches comparative health systems, health economics, and health care financing. She earned her S.B. from National Taiwan University, and her M.S. and Sc.D. from Harvard University, and she was also a Takemi Fellow at Harvard (2004-2005) and an Honorary Professor at Hong Kong University (2007-2009). Her research focuses on 1) the equity issues of the health care system; 2) impact of the NHI program on health care market and household consumption patterns; 3) comparative health systems in Asia-Pacific region. She has served as one of the co-principal investigators of the EC-sponsored research project (EQUITAP), and also a principal investigator of the International Quality of Life Assessment Project (Health Assessment Lab, U.S.). She has also been appointed to serve as a member on various government committees dealing with health care issues in Taiwan, such as National Health Insurance Supervisory Committee (DOH), National Health Insurance Actuarial Committee (DOH), Hospital Management Committee (DOH), Hospital Global Budget Payment Committee (BNHI), Health Insurance Committee, NHI Forum (NHRI), and Task Force on NHI Case Payment (BNHI). Dr. Lu received the Minister Wang Jin Naw Memorial Award for Best Paper in Health Care Management presented by Kimma Chang Foundation in 2002 and she has published papers in Health Affairs, Medical Care, Journal of Health Economics, Health Economics, Social Science and Medicine, Health Economics, Policy and Law, Osteoporosis International, Health and Quality of Life Outcomes, and Taiwan Economic Review etc, and a book "Health Economics" (in Chinese).

A detailed C.V. can be found at http://hcm.cgu.edu.tw/ENG/faculty/rachel.htm.



GIOTA PANOPOULOU

ADVISOR TO THE FINANCING DIRECTOR INSTITUTE OF SOCIAL SECURITY MEXICO

Giota Panopoulou is currently an advisor to the Financing Director of the Mexican Social Security Institute, the largest social security institution in Latin America covering approximately 40 million private employees and their families. Before joining the Mexican Social Security Institute, she served as a Director of Health and Economic Development at the Mexican Ministry of Health, as well as an Economist and Long-term Consultant in the World Bank, working at the Human Development Groups of the Europe and Central Asia Region, East Asia and Pacific Region and Latin America and the Caribbean Region. The areas of her expertise are health financing, health insurance, design, implementation and evaluation of health reforms, public sector institutional restructuring and health and migration issues. She has extensive experience of Mexico and Colombia, but has worked on countries in Europe, Central Asia and East Asia. She holds a PhD in Economics from the University of Sussex (UK) and an MSc. in Economics for Development from the University

ADAM WAGSTAFF



RESEARCH MANAGER THE WORLD BANK

Adam Wagstaff is Research Manager of the Human Development & Public Services team in the Development Research Group. He holds a DPhil in economics from the University of York (U.K.). Before joining the Bank, he was a Professor of Economics at the University of Sussex. He was an associate editor of the Journal of Health Economics for 20 years, and has published extensively on a variety of aspects of the field, including: health financing and health systems reform; health, equity and poverty; the valuation of health; the demand for and production of health; efficiency measurement, and illicit drugs and drug enforcement. Much of his recent work has been on health insurance, health financing, vulnerability and health shocks, and provider payment reform. He has extensive experience of China and Vietnam, but has worked on countries in Africa, Latin America, S Asia, and Europe and Central Asia, as well as other countries in E Asia. Outside health economics, he has published on efficiency measurement in the public sector, the measurement of trade union power, the redistributive effect and sources of progressivity of the personal income tax, and the redistributive effect of economic growth.

PARALLEL SESSION 2.4:

PUBLIC STEWARDSHIP OF PRIVATE PROVIDERS:

THE ROLE OF HEALTH INFORMATION SYSTEMS





RICHARD COKER

PROFESSOR OF PUBLIC HEALTH, LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE.

Richard Coker is a Professor of Public Health at the London School of Hygiene & Tropical Medicine. He currently heads the Communicable Diseases Policy Research Group (CDPRG), which provides a focus of expertise on the diverse public health problems associated with communicable disease control internationally. The group's current research focus is supporting preparedness for pandemic influenza in SE Asia, the likely epicenter of emerging infectious diseases including pandemic influenza. It has also developed a research consortium that includes partners from Thailand, Vietnam, Cambodia, Laos, Indonesia and Taiwan to evaluate health systems responses and support governments' responses in the event of a pandemic.



PHAL DES

DIRECTOR, IT CENTER ROYAL UNIVERSITY OF PHNOM PENH (RUPP).

Prof. Ir. Phal Des is the Director of the IT Center of Royal University of Phnom Penh (RUPP): B.Sc. (Mathematics), RUPP, 1992; Diplôme d'Etudes Spéciales en informatique Appliquée aux Science de L'Education, Université Libre de Bruxelles (Belgium), 1998.

Prof. Des has spent over 3 years of research in Auto-Learning and Auto-Evaluation at the Univertité Libre de Bruxelles (ULB) in Belgium. As a member of the Counterpart of the Center of the International Cooperation for Computerization (CICC), Prof Des is the Chief of the IT Committee of Engineering Institution of Cambodia (EIC).

DES is also the program coordinator for Master of Science in Information Technology Engineering (MITE) and he has access to a wide network of people and resources in the field of IT Engineering. His focus is on training students, faculty and staff at RUPP in a variety of modern ICTs and engaging RUPP in regional and international research projects and activities. From 2005 to 2007 he worked on projects such as the Greater Mekong Sub-region Virtual University project and the "Open Source e-Learning" project of UNESCO Paris. In 2007 he was awarded a Obuchi/UNESCO fellowship to work on a project called "System Support for Mobile and Distributed Multimedia Computing" in collaboration with the University of Technology of Dresden, Germany. During 2007-2008, he also worked on e-health and e-education projects with WASEDA University and KDDI Japan. The project was aimed at providing to people in rural areas better communication with doctors and teachers in Phnom Penh city. In 2009 he was awarded with the title of research fellow in e-media & Virtual Reality from Group T, National University College Leuven, Belgium.

Currently he is working on multiple projects such as Mapping Healthcare Centres in Cambodia, Presumptive Diagnosis and Awareness for STDs via SMS for Young Cambodian in Rural Areas, and mobile Computing and 3G Wireless Networks for health care, education and heritage.



DAVID DE FERRANTI

PRESIDENT RESULTS FOR DEVELOPMENT INSTITUTE

David de Ferranti is President of the Results for Development (R4D) Institute, a Washington-based not-for-profit focusing on developing countries. R4D combines idea generation (e.g., policy research) with catalytic action (e.g., piloting innovative policy options on the ground), particularly in health, governance, education, and creative finance for small and medium enterprise development.

He has over thirty years of experience in leadership and management roles in the public and private sector, chiefly on international development and, earlier, U.S. public policy. Before founding R4D, he was at the World Bank for over two decades, where, as part of its top management team, he headed up programs aiding African, Asian, and Latin American countries. From 1999 to 2005, as the Bank's Regional Vice President for Latin America and the Caribbean, he was responsible for a \$25 billion loan portfolio, 700 professionals in 14 locations, and a \$160 million budget. From 1994 to 1999, in another senior role at the Bank, he oversaw its research and financial support to developing countries in the areas of health, education, nutrition, and other social services.

In addition, he has been a resident Senior Fellow at the Brookings Institution, a Senior Advisor at the United Nations Foundation, an Adjunct Professor at Georgetown University, an advisor to Carlos Slim and his infrastructure investment group in Latin America, and an advisor to an emerging high-tech enterprise, and has held management positions at Rand (the think tank), and in the U.S. government.

He holds a Ph.D. in Economics from Princeton University, with Outstanding Dissertation Award honors, and a Bachelors degree from Yale University, with Phi Beta Kappa and Magna cum Laude honors.

He is the Chair of the Board of the Center on Budget and Policy Priorities, and serves as Chair or Co-Chair of The Health Financing Task Force, The Task Force on Health Workforce Costs and Financing, and The Working Group on AIDS Costs and Financing. Other board memberships have included: The Rockefeller Foundation (where he chaired the Finance Committee overseeing the investment of the Foundation's \$3 billion endowment); Transparency International -USA; The Inter-American Dialogue; The Pew Memorial Trust International Health Advisory Panel; Technoserve, Inc.; The Center for Global Development Advisory Panel; The Lewis T. Preston Education Program; The Escuela Nueva Foundation; and The Partnership for Educational Revitalization in the Americas.

His research, writing, and management experience have concentrated on health, education, innovative financing, good governance (and transparency), small and medium enterprise development, economic policy, nutrition, poverty reduction, and urban and rural development, population, pensions, tax policy and finance, environmental protection, transport, and water supply and sanitation. His publications include over 70 articles, papers, op-eds, book-length reports, and contributions to edited volumes.

He is a US citizen by birth, with Australian, Belgian, Italian, South African, British, and Dutch roots. He has lived in nine U.S. states, plus Britain, the Netherlands, and Belgium, and has worked for extensive periods in Latin America, Africa, Asia, and Europe.

KRISHNAMURTHY (GOPI) GOPALAKRISHNAN



PRESIDENT WORLD HEALTH PARTNERS

Gopi Gopalakrishnan is the President of World Health Partners. Mr. Gopalakrishnan has over 20 years of experience in implementing large-scale service-delivery programs in lowresource settings. He founded Janani, a non-profit entity devoted to providing child and reproductive health services, in one of the poorest regions of India. Today, Janani accounts for more than 20% of family planning in the state of Bihar. Mr. Gopalakrishnan's network management strategies have been recognized worldwide as some of the most effective methods of addressing the great unmet need for family planning, and have been supported by the Government of India.



FOLA LAOYE

CHIEF EXECUTIVE OFFICER HYGEIA-NIGERIA LIMITED

Mrs. Fola Laoye – Mrs. Laoye holds a Bachelors Degree in Accounting from the University of Lagos, Nigeria and a Masters of Business Administration from Harvard Business School, Cambridge, USA. She is also an Associate Member of the Institute of Chartered Accountants in England & Wales and the Institute of Chartered Accountants of Nigeria. Fola has had nineteen years of business experience, both locally and internationally, having trained with Ernst & Young, Lagos and Price WaterHouse Coopers in London. She is currently the Chief Executive Officer of Hygeia Nigeria Limited, promoters of Hygeia HMO, the foremost health maintenance organization in Nigeria and the Lagoon Hospitals group. While with Hygeia, she has been responsible for the start up and growth of the Hygeia HMO business and the Hygeia Community Health Plan as well as the roll-out of two ultra-modern medical facilities in Lagos. She is also a Trustee of the Hygeia Foundation, the capacity-building arm of the Group, which is currently focused on buildingbothclinicalandmanagerialskillsofhealthcareprovidersin Nigeria. She lectures part-time at the Lagos Business School (Pan-African University) in the area of Strategy and Business Policy.

FRANK RIJSBERMAN

DIRECTOR PROGRAM GOOGLE

Dr Frank Rijsberman joined Google.org, the philanthropic arm of Google Inc., in June 2007, where he is Director Program, responsible for Google.org partnerships in the areas of health, geo and environment. Prior to joining Google, Frank was Director General (CEO) of the non-profit research institute International Water Management Institute (www.IWMI.org), with HQ in Sri Lanka. After starting his career as a researcher at Delft Hydraulics Laboratory, he co-founded and managed an environmental consultancy firm in the Netherlands, Resource Analysis BV. Rijsberman holds a BSc and MSc from Delft University of Technology in Civil Engineering and a PhD from Colorado State University in Civil Engineering (Water Resources Planning and Management). He was a Professor at UNESCO-IHE International Institute for Water Education from 1999-2008, jointly appointed at Wageningen University from 2003-8.

PLENARY SESSION 3:

ENHANCING GLOBAL HEALTH SECURITY:

INFORMATION SYSTEMS AS THE FOUNDATION OF EFFECTIVE PANDEMIC PREPAREDNESS AND RESPONSE

Global Health Information Forum
ISSUES TO BE COVERED:

1) Do you think that the International Health Regulations (IHRs) are effective? If not how can we make them more effective?

- The Revised International Health Regulations: rationale and road map for implementation
- What are the factors most likely to determine IHR compliance?
- Accelerating national core-competencies to reach compliance with the IHRs: what's involved?
- How to build trust to share information on a real-time basis without facing the risk of adverse economic consequences?

2) Is regional networking an answer to improve the rapid sharing of disease outbreak information?

1. New "glocal" tools and networks for disease surveillance: pathfinders for health information systems and global health cooperation of the future?

3) Technical and political dilemmas in accurate reporting of outbreak diseases:

- Problems of diagnosis -- what is it? Who does it? How is information shared?
- Problems of assessment of the magnitude of the problem?
 -- passive or active surveillance? Why are there never any denominators?
- Problems of reporting -- is there a problem?
 Is it reportable? Consequences of reporting such as profiling, travel restrictions etc.

4) Should surveillance systems for pandemics stand alone or should they be fully integrated into health information systems?



RICHARD CASH

SENIOR LECTURER ON INTERNATIONAL HEALTH HARVARD SCHOOL OF PUBLIC HEALTH AND FORMER PRINCE MAHIDOL AWARDEE

Richard A. Cash, MD, MPH is a Senior Lecturer in the Department of Population and Global Health at the Harvard School of Public Health (HSPH) and presently visiting Professor (Public Health) and Advisor in Global Health at the Public Health Foundation of India (PHFI). Dr. Cash began his career in international health over 40 years ago at what is now the ICDDR,B in Dhaka, Bangladesh where he and his colleagues conducted the first clinical trials of Oral Rehydration Therapy (ORT) in adult and pediatric patients with cholera and other infectious diarrheas. Their early community-based trials of ORT were greatly expanded in the late 70's by WHO and NGOs such as BRAC so that today ORT is used throughout the world and saved millions of lives. Since joining Harvard University 32 years ago as a Fellow at the Harvard Institute for International Development and as a faculty member of the Harvard School of Public Health, he has been engaged on a number of international programs that stressed research implementation, training, and capacity building in developing country institutions. At HSPH he conducts courses on: policies and implementation issues global health; the social, political, and economic determinants of infectious diseases; and research ethics. He also lectures extensively, both at Harvard and internationally on various aspects of global and child health, and infectious diseases. As Director of the Program on Research Ethics at HSPH he has overseen the training of international fellows, and conducted workshops at HPSH on research ethics and over 30 workshops in 10 countries. In addition to his present position at PHFI, he has visiting faculty appointments at the following institutions: the Achutha Menon Centre for Health Sciences Studies at the Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST) in Trivandrum, Kerala, India; the James P. Grant School of Public Health (JPGSPH) at BRAC University in Dhaka, Bangladesh; and the Center for International Collaborative Research at the University of Nagasaki in Nagasaki, Japan. In January 2007, he was presented with the Prince Mahidol Award in Public Health for his work on the development and use of Oral Rehydration Therapy.

BOUNLAY PHOMMASACK

DEPUTY DIRECTOR MINISTRY OF HEALTH LAO PDR

Dr. Bounlay Phommasack, Deputy Director General, Department of Hygiene and Prevention, Ministry of Health, Laos, and "Executive Member" of the MBDS Network, has been working in the area of public health for more than 25 years. The first half of this period has been working at provincial level focusing more at district health system strengthening and front line health services, and the second half of this period until now, working at ministerial level concentrated more on emerging and re-emerging infectious diseases such as HIV/AIDS, TB, Malaria and Dengue. Graduated on Master Public Health (MPH) in Antwerp, Belgium since 1991.

Since 2001 with the initial support of The Rockefeller Foundation as an "added value" together with countries in Great Mekong sub-region formed the Mekong Basin Disease Surveillance network, where tools as well as mechanisms for information exchange between neighboring provinces, between GMS countries have been developed, thus facilitating sub-regional collaboration for dealing with any public health emergency for international concerns such as SARS, Avian Influenza H5N1 and Pandemic Influenza H1N1. With experiences on public dealing with HIV/AIDS, TB and Malaria activities, Dr. Bounlay Phommasack, has been appointed since 2003 until now, as Director of the "Global Fund to Fight HIV/AIDS, TB and Malaria" Project at Ministry of Health Laos.

Because Avian Influenza and Pandemic Influenza go far beyond the responsibility the responsibility of the health sector, Dr. Bounlay Phommasack since 2007, has been appointed as DirectoroftheNationalEmergingInfectiousDiseasesCoordination Office (NEIDCO). The NEIDCO Office serves as secretariat for the Prime Minister Office working closely with different sectors, requiring common efforts for better prevention and control of communicable diseases. This inter-sectoral coordination mechanism playing an important role for effective and efficient non pharmaceutical interventions particularly during the current H1N1 pandemic. Under the cooperation and collaboration with ASEAN, Dr. Bounlay Phommasack, has been delegated with 2 additional positions such as Head of ASEAN Expert on Communicable Diseases so called "AEGCD" and Associate Chair of Senior Officer on Health Development so called "SOMHD" at the Ministry of Health, Laos.



GUENEL RODIER

DIRECTOR OF INTERNATIONAL HEALTH REGULATIONS WORLD HEALTH ORGANIZATION

Richard A. Cash, MD, MPH is a Senior Lecturer in the Department of Population and Global Health at the Harvard School of Public Health (HSPH) and presently visiting Professor (Public Health) and Advisor in Global Health at the Public Health Foundation of India (PHFI). Dr. Cash began his career in international health over 40 years ago at what is now the ICDDR,B in Dhaka, Bangladesh where he and his colleagues conducted the first clinical trials of Oral Rehydration Therapy (ORT) in adult and pediatric patients with cholera and other infectious diarrheas. Their early community-based trials of ORT were greatly expanded in the late 70's by WHO and NGOs such as BRAC so that today ORT is used throughout the world and saved millions of lives. Since joining Harvard University 32 years ago as a Fellow at the Harvard Institute for International Development and as a faculty member of the Harvard School of Public Health, he has been engaged on a number of international programs that stressed research implementation, training, and capacity building in developing country institutions. At HSPH he conducts courses on: policies and implementation issues global health; the social, political, and economic determinants of infectious diseases; and research ethics. He also lectures extensively, both at Harvard and internationally on various aspects of global and child health, and infectious diseases. As Director of the Program on Research Ethics at HSPH he has overseen the training of international fellows, and conducted workshops at HPSH on research ethics and over 30 workshops in 10 countries. In addition to his present position at PHFI, he has visiting faculty appointments at the following institutions: the Achutha Menon Centre for Health Sciences Studies at the Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST) in Trivandrum, Kerala, India; the James P. Grant School of Public Health (JPGSPH) at BRAC University in Dhaka, Bangladesh; and the Center for International Collaborative Research at the University of Nagasaki in Nagasaki, Japan. In January 2007, he was presented with the Prince Mahidol Award in Public Health for his work on the development and use of Oral Rehydration Therapy.



MIRIAM WERE

BOARD OF TRUSTEES, UZIMA FOUNDATION

1. OVERVIEW

Born in 1940 in Lugala village, Western Province in Colonial Kenya, Miriam has lived through tremendous changes in her life. The first 8 years of education was in schools sponsored by the Friends (Quaker) Church since colonial Kenya did not provide education for the "natives". In spite of this, she sailed through High School, went to study in USA in the early 1961 under Church sponsorship. She graduated in 1964 with a Composite Major in Biology, Chemistry and Physics. She got admission to Medical school in USA but not having been home at all since 1961, she returned to Kenya in 1965 The newly Independent Kenya Government was looking for Science teachers and sponsored her study at Makerere but not for Medicine but for a Postgraduate Diploma in Education. She qualified to teach high School Biology, Chemistry and Physical Education in June 1966 and got married that same year to Humphreys R. Were

While teaching at High school was fun, teaching sick children was not. So as a wife and mother and with the support of her husband, she enrolled in the newly established Medical School at the University of Nairobi. With the support of Humphreys and their children, Miriam completed the 5-year Medical School course in 1973 followed by a year of internship and a period of service in the Ministry of Health, Kenya. Towards the end of 1974, she was recruited to teach in the Department of Community Health in the Faculty of Medicine, University of Nairobi.

While attached to this Department, she got opportunity to study at the Johns Hopkins University for the Masters and then Doctorate of Public Health degrees. She subsequently became the Chairman of this department and established the first Master of Public Health program in Kenya in 1983. In 1985, she was recruited by UNICEF to work in Ethiopia in an even more challenging health environment. In 1990-1993, she became the Representative of the World Health Organisation in Ethiopia. Between 1993 and 2000 when she retired from the UN, she was the Director of UNFPA heading a team that provided technical services in Population and Reproductive Health in East, Central and Anglophone West Africa.

2. HONOURS AND CURRENT MEMBERSHIPS ON BOARDS:

A) co-sponsor of and on the board trustees, UZIMA Foundation from 1995 to date. UZIMA has a focus on youth empowerment. B) on Global Health Workforce Alliance board that addresses the global crisis in the shortage of human resources for health C) on the International Award Committee of the Prince Mahidol Award Foundation D). A member of the Champions for HIV-Free Generation chaired by the former president of Botswana and consisting of other former heads of states from Mozambique, Tanzania, Zambia and notables like Desmond Tutu and Justice Cameron, since 2008 to date. E) on the advisory board of the Global Philanthropy Alliance since 2007 to date. E) On the board of directors, MAP International.

2008: THE HIDEYO NOGUCHI AFRICA PRIZE; Japan's equivalent to the Nobel.
2008: KNIGHT in the French National Order of the Legion of Honour for distinguished service in health and development in Africa with particular emphasis to children, mothers and youth
2009: at Buckingham Palace, London, represented Kenya at the 60th Anniversary of the Commonwealth
2007: THE QUEEN ELIZABETH II GOLD MEDAL PUBLIC HEALTH for Outstanding Contributions to International Public Health in the Commonwealth
2007: The WORLD YWCA TRAIL BLAZER AWARD in the category of Women Leading Change for lifelong commitment to improving the health of disadvantaged people. 2005:
2005: On Kenya's National Day, 12TH December, presented by President Kibaki,

ELDER OF THE ORDER OF THE BURNING SPEAR (EBS) of the Republic of Kenya for "distinguished service rendered to the nation"

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PARALLEL SESSION 3.1:

IMPROVING TRANSPARENCY THROUGH COLLABORATION ACROSS SECTORS



IMPROVING TRANSPARENCY THROUGH COLLABORATION ACROSS SECTORS

INTRODUCTION

The design and implementation of national development plans such as poverty reduction strategies and sectoral strategies and interventions, as well as the objective of achieving the Millennium Development Goals by 2015, have substantially increased the demand for good development data, including a strong emphasis on health information. This, in turn, has increased pressures to improve the quality, coverage and usage of relevant statistics through more effective and better coordinated national statistical systems (NSSs). Analysts and users of statistics need a wide range of data from a variety of sources in order to design appropriate policies and programmes and to monitor and evaluate their effects and impacts.

The National Strategy for the Development of Statistics (NSDS) approach was developed to improve strategic planning of NSSs and their coordination and coverage; and to mobilise national and international resources to enable developing countries to respond to weaknesses in their production and use of statistics. It is vital that national data producers - in particular National Statistical Offices (NSOs) and sectoral statistics units, such as in ministries of health - work closely together and with data users, and that sectoral statistical systems, such as the health information system (HIS), should be harmonized and integrated as part of the NSS in order to maximize access to and use of good quality information in policy processes.

This session will discuss how increased integration and sharing across sectors can be achieved to improve the availabilityandqualityofdataforpublichealthdecision-makingand implementation. It will follow three main themes:

- 1. Connecting health information plans with NSDSs
- 2. Improving health information through involvement of all sectors to identify and measure the socio-economic determinants of health
- 3. The need for transparency and data sharing

INTER-RELATIONSHIP BETWEEN HEALTH AND OTHER SECTORS

The context for this session is the very wide range of relationships between health sector policies, issues and outcomes, and those of other sectors. A recent, controversial example from the UK serves to underline the diversity of these linkages. The Durham and Darlington Primary Care Trust has pledged £1 million to Durham County Council to pay for gritting of extra paths and pavements and additional road gritting during icy periods. The aim is to reduce the number and consequences of road traffic accidents; and to improve the quality of life for the elderly by avoiding falls and fractures occurring in icy weather. On the other hand, it has been argued that there are many more relevant and under-funded healthrelated services that could have benefitted old people more directly. This example shows how far ranging the implications of actions taken by other sectoral administrations can be on public health - and the wide range of issues in other sectors that health administrations may want to influence in order to achieve health goals.

Few developing countries face the UK's climatic conditions but the same principles and arguments apply to road maintenance (e.g. filling pot holes) and issues in other sectors such as education, energy, governance, etc.

NSDS AND HIS

The NSDS approach has been developed by PARIS21 partners since the inception of the partnership in November 1999, with a major milestone being the central role given to NSDSs in the Marrakech Action Plan for Statistics (MAPS) that was adopted by the Second International Roundtable on Managing for Development Results, in February 2004. MAPS called for all low income countries to design and implement NSDSs, with a view to having better data to monitor progress towards national and international development goals by 2010. By mid-2009, 33 out of 78 low income countries and 23 out of 39 lower-middle income countries were implementing an NSDS. A further 18 low income countries and 7 lower-middle income countries were either designing an NSDS or awaiting its adoption.

In many countries sectoral issues and concerns are not given sufficient attention in consideration of national statistics. Sectoral systems tend to be under-resourced and statisticians from sectoral ministries are often largely isolated and inadequately involved in processes to develop national statistics. The NSDS approach advocates for better strategies for better data and aims to strengthen statistics across the entire NSS, including all health-related information.

While many first generation NSDS still focus on statistics managed by the NSOs, experience is showing that those countries that are embarking on their second or subsequent NSDSs show improvements in ambition, achievement and scope - notably by extending strategic planning beyond the National Statistical Office to encompass sectors. Examples are progress made in implementing second and third generation NSDSs in Uganda, Malawi, Mozambique, and Lao PDR.

Figure 1 illustrates the important cross-linkages between NSOs and sectoral statistical units, as well as between the sectoral units in a truly integrated NSS.



FIGURE 1: INTEGRATED NATIONAL STATISTICAL SYSTEM

COLLABORATION ACROSS SECTORS, INCLUDING THE NEED FOR TRANSPARENCY AND DATA SHARING

Cross-linkages between sectors have consequences for the variety of information that is relevant to health policy processes; and to the components of an NSS relevant to a comprehensive health information system. Returning to our earlier example, the decision to fund extra gritting by the UK Primary Care Trust will presumably have taken account of information about the impact of un-gritted icy roads and paths on road traffic accidents and falls; and the impact of those incidents on health.

Figure 2 is taken from the Health Metrics Network Framework. It emphasises the importance of integrating into health information systems population-based data from different sources - including censuses, civil registration, and population surveys - with health institution-based data sources. Implicit in the diagram is that some of these data sources come from other sectors, including education, transport, energy, etc.



FIGURE 2: HEALTH INFORMATION DATA SOURCES

It is vital that statistics from these different sources are accessible and readily understood and usable in the broader context beyond their primary focus and origins. Their value is greatly enhanced if indicators and other statistics are coordinated and comparable between different sources. But coordination, harmonization and accessibility imply a need for levels of effective communication and working relationships beyond what is normally present between all producers of statistics (as well as with other stakeholders in the NSS, including the providers, analysts, users and funders of statistics). This collaboration needs to encompass: statistical policies and strategic planning; coordination of statistical processes; harmonization of sources, concepts and definitions; accessibility and sharing of information; analysis; as well as dissemination. All of these aspects should be considered in NSDS and HIS design and implementation processes, and communication should be assured through policy-making and stakeholder consultation mechanisms, led for instance by a high-level National Statistical Council or Board and including cross-sectoral working groups and bilateral relations between the NSO and sectors and between sectors.

Strong leadership and a clear vision are key in deciding nationally about what statistics are needed most (rarely can all be provided, priorities need to be determined), how they can be produced most efficiently, and how statistics from different sources can be merged to triangulate and add value across the NSS. Taking a narrow view about what is best for the sectoral ministry; and/or doing what has been done before; and/or doing what can most readily be funded (e.g. from external resources) will not satisfy these criteria. Communication is needed across the sectors, coupled with a strong policy direction about statistics, and steps to build up sectoral systems towards a shared vision for national statistics. It is clear that there is much implied by the dotted line to the Department of Statistics and other sectors in figure 3.

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FIGURE 3: ASSESSING SECTORAL SYSTEMS, E.G.: HEALTH INFORMATION SYSTEM

HOW INFORMATION SYSTEMS NEED TO BE DEVELOPED FOR BETTER COLLABORATION ACROSS SECTORS?

The NSDS should provide a framework for all official statistics to under-pin consistency, coordination and efficiency. Many developing countries are still suffering from chronic weaknesses typified by a vicious cycle of underfunding and weak supply of statistics leading to low demand and little incentive for increased resources for statistics. Many of the poorest and most vulnerable countries, who are most in need of good statistics, are in the worst position to produce and use them. Such countries need to break out of the vicious cycle by increasing the demand for statistics, by making better use of existing and new resources, and by producing better statistics. To start with they will need to concentrate on statistics that are the highest priority for their key users, while advocating for increased investment in statistics that will pay itself many times over.



FIGURE 4: BREAKING OUT OF THE VICIOUS CYCLE

The HMN Framework notes that country HIS strengthening must start with a broad-based assessment of priority needs – for policy-makers and planners. It notes that some types of information are more important than others and that indicators will vary between countries and must be linked to a broader national statistics strategy (NSDS), and notably a poverty-monitoring masterplan in countries with a Poverty Reduction Strategy. This applies equally to other sectors and national statistics as a whole.

The NSDS guidelines do not advise countries on what statistics they should collect, or how they should collect them. These decisions are left for national stakeholders to make, taking account of the particular needs of their country, including their priorities and resources, as well as international recommendations, norms and standards. The expectation is that decisions on what statistics to collect will be made through an inclusive, participatory process involving government, private sector, academia, civil society, etc. with tough decisions made at a senior level, for instance by a National Statistical Council; with decisions on concepts, methods and standards left to the appropriate technical experts.

Concrete steps that NSDS and HIS design and implementation teams can take, include:

• Firstly, move quickly to more fully integrate sectoral statistics

into the NSS, ensuring a focus on the highest priority statistics, as outlined above and described more fully in NSDS and HMN guidance (see references).

 Secondly, promote better collaboration generally between statisticians, data analysts, policy-makers (including Parliamentarians) and planners, private sector, civil society and the media, taking an NSS-wide view of issues and

priorities.

- Thirdly, improve the availability, quality and use of existing household survey data, for instance through the Accelerated Data Programme (ADP - established as another of the recommendations of the Marrakech Action Plan for Statistics). Currently, 52 countries are participating in this programme's first phase, which assists countries to develop documentation, archiving and access to household survey data.
- Finally, by pursuing advocacy for statistics awarenessraising efforts are necessary to ensure greater engagement of stakeholders in NSDS and HIS processes.

CONCLUSION

If collaboration across sectors is seen as a priority for a country,

it should be reflected in NSDS and HIS processes where all national stakeholders concerned with the question of measuring

development as a whole should be involved.

Data needs and their articulation as demands for statistical information are at the heart of NSDS. So long as the needs for joined-up sectoral information systems, such as HIS, are identified - and their importance recognized, prioritised and funded by stakeholders - NSDSs can play a fundamental role in developing those systems as part of a coordinated and truly integrated NSS.

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MOHAMED-EL-HEYBA BERROU



MANAGER OF THE PARIS21 SECRETARIAT OECD

Mr. Mohamed-El-Heyba Lemrabott Berrou joined the OECD in March 2009 as Manager of the PARIS21 Secretariat at the Development Co-operation Directorate.

Mr. Berrou, a Mauritanian national, has over 8 years of experience as an Advisor in charge of the "Studies, Analysis & Evaluation" Unit, then as Director of Studies and Planning at the Human Rights, Poverty Reduction & Social Integration (Government) Commission. He was responsible for the design, monitoring and evaluation of targeted poverty reduction programs as well as conducting studies aiming at better understanding and monitoring of poverty and poverty related issues (poverty profiles, qualitative and quantitative surveys, etc.).

Following the launch of the Poverty Reduction Strategy Paper (PRSP) process by the international community, he was appointed Coordinator of the participative process in his country in September 1999, in addition to his duties above. In this capacity, he coordinated the design of the first and second generation PRSPs of Mauritania, the production of annual progress reports, and the establishment of a Monitoring and Evaluation Unit, and participated in the organization of donor roundtables.

In August 2007, he was appointed Senior Advisor to the democratically elected President of the Islamic Republic of Mauritania. He was in charge of the "Productive Sectors, Infrastructure and Land Planning" Unit. His duties included: advising the President on policies in numerous sectors (mining, oil & gas, agriculture, fisheries, livestock, water, energy, industry, environment, ICTs, tourism, etc.), monitoring the implementation of Government Action Plans and Presidential instructions, and contributing in the preparation of Presidential official visits and participation in relevant Summits.

Mr. Berrou, who prefers to be called Abadila, holds two MSc degrees in Mathematics and Applied Mathematics from the University of Arizona (USA), as well as a Master's degree in Applied Mathematics from the University of Paris-VII (France).



ALAN LOPEZ

HEAD, SCHOOL OF POPULATION HEALTH, UNIVERSITY OF QUEENSLAND, AUSTRALIA

Professor Alan Lopez is Professor of Medical Statistics and Population Health and Head of the School of Population Health at the University of Queensland. Prior to joining the University in January 2003, he worked at the World Health Organisation in Geneva, Switzerland, for 22 years where he held a series of technical and senior managerial posts including Chief epidemiologist in WHO's Tobacco Control Program (1992-95), Manager of WHO's Program on Substance Abuse (1996-98), Director of the Epidemiology and Burden of Disease Unit (1999-2001) and Senior Science Advisor to the Director – General (2002). He is also an Affiliate Professor of Global Health at the Institute for Health Metrics and Evaluation at the University of Washington.

He is a highly cited author whose publications have received worldwide acclaim for their rank in importance and influence in health and medical research (with over 10,000 lifetime citations). He has published over 200 peer-reviewed journal articles, books, letters and book chapters on mortality analysis and causes of death, including the impact of the global tobacco epidemic, and on the global descriptive epidemiology of major diseases, injuries and risk factors. He is the co-author with Christopher Murray of the seminal Global Burden of Disease Study (1996) which has greatly influenced debates about priority setting and resource allocation in health. His 2006 Lancet paper (lead author) with Murray and colleagues was listed among the 25 best publications in health and medical research worldwide in that year. Three of his Lancet papers with Murray have each been cited more than 1000 times.

He is the co-author (with Sir Richard Peto) of the Peto-Lopez method which is widely used to estimate tobacco-attributable mortality to support policy action. He, Sir Richard and others recently published a second (online) edition of their seminal book on Mortality from Smoking in Developed Countries. He was awarded the Leverhulme Prize (with Sir Richard Peto) by the Liverpool School of Hygiene and Tropical Medicine in 1998 for his contributions to epidemiology and international health.

Professor Lopez is on the editorial board of PLoS Medicine and Preventive Medicine, and co-Editor in Chief of Population Health Metrics. He is a member of the Wellcome Trust Population and Public Health Funding Committee (2007-2010), the WHO Expert Committee on NCD Surveillance (2009-2011), the US National Academy of Sciences Panel on Divergent Trends in Longevity (2008-2011), the Scientific Board of the Oxford Health Alliance Grand Challenges in Non-Communicable Disease (2006-2009), and was former Chair of the Health and Medical Research Council of Queensland. He was recently elected as a Foreign Associate Member to the Institute of Medicine of the U.S National Academies of Sciences.



JASAP DAM NAGARI-POPOITAI

ADVISOR, PSRMU, DEPARTMENT OF PRIME MINISTER & NATIONAL EXECUTIVE COUNCIL, PAPUA NEW GUINEA

I commenced formal employment in the Public Service in 1984 with National Statistical Office (NSO). My primary role in NSO was predominantly in research and development on all the technical aspects of data collection, processing and analysis. I learnt through hands on experience, the entire process of designing Census to large scale surveys. Apart from the application of statistical methodology to detailed analysis of the 1980 Census, I participated in the 1990 Census of population and housing as the Master Trainer and Quality Control Supervisor. While with NSO, we conducted the first ever Demographic and Health Survey (DHS) in 1996. I was part of the three people Team who designed the DHS Questionnaires and wrote the various Manuals.

In September 1998, I was seconded to the Department of National Planning and Rural Development where I was attached to the Development Planning and Programming Division till 2006 when I moved to Development Policy Division on a promotion transfer basis. In the Department, I have been involved actively in sector policy development and strategies, sector development plans, Provincial Plans formulation, planning and programming of projects within the various sectors.

Throughout my career with the Government as a public servant (especially when I joined Planning), I have worked closely with the private sector, particularly mining industry mostly on issues pertaining to Mine Closure, Women in Mining and more recently, the Women and Children in the Mine Impacted communities.

The highest level of planning which I have undertaken is being part of the team that developed The Papua New Guinea Vision 2050 'a home-grown' initiative which spells out the aspirations of our people. Currently I am engaged as Advisor to the Department of Prime Minister and National Executive Council on all matter pertaining to Strategic Planning. I enjoy working in a Team environment and can work comfortably in multi cultural situations. As a Planner, I see the lack of appreciation of data as a prerequisite to sustainable planning. Planning without good data in my view is an intellectual crime

COMMUNITY SERVICE

GOLF

I work behind the scene supporting my husband – Mr. Benny Popoitai – in organizing what in commonly known in the Golfing community as the 'Heart - to – Heart Golf Trade Day' a major fund raiser for the Sir Buri Kidu Heart Institute. This initiative commenced on the first Friday in June, 2004 and has grown in terms of the number of corporate entities that support. A major indicator being the amount of funds raised in one single day. This year (2008), we raised over K120, 000.00. In the last two years we have been fund raising to build a Four Bed Unit within the Heart Institute for heart patients who are currently being cared for in the Insensitive Care Unit. It is an initiative that we are committed to and will continue till it is accomplished.

ACHIEVEMENT

We purchased the first ever mobile Echo- Cardiac machine for the Heart Institute in 2006 at the cost of approximately K260, 000.00.

Through the UNFPA Population Project, I led the Team that provided seed funding of approximately K30,000.00 and worked closely with Boroko Rotary Club to host the first ever 'Population Golf Trade Day' – an initiative we committed to raised awareness in the private sector on population issues. This year (2008) the Theme was 'It is a Right Lets Make it Real' and was commemorated on 11th July.

ACHIEVEMENT

We raised over K60, 000.00 on the 11th of July 2008. All these funds are earmarked for the University of PNG Clinic extension of the Reception and waiting room. Boroko Rotary Club is the implementation agency and also fund manager.

VILLAGE PLANNING COMMITTEE

During times when I take my holidays back in my village (Busamang village), I participate in the community activities – one such being the Village Planning Committee Meetings where

I am usually invited to sit in and provide technical input as and where the need is.

ACHIEVEMENT

A comprehensive Project Design Documentation which resulted in an PIP worth K33, 000.00 for construction of two double classrooms and three teachers houses. Project completed and opened/dedication in August 2008.



IVO NJOSA

COORDINATOR HEALTH INFORMATION SYSTEMS; HEALTH, NUTRITION AND POPULATION HUMAN DEVELOPMENT NETWORK, THE WORLD BANK

Ivo Njosa is been in the developing arena for more than twenty years. He is currently a coordinator for health information systems (HIS) with the Human Development Network in the World Bank. He is leading the effort to increase Bank lending support to strengthening country HIS using the HMN framework for HIS strengthening. His position at the Bank is funded by the HMN. He has lived and worked across the globe and has extensive experience in capacity building in Statistics, Data management and ICT. He has worked in Statistics offices in C.A.R, Liberia, and Rwanda. Before re-joining the World Ban he worked with various UN agencies and other international agencies mostly in the area of data management and information systems development. He has a Masters in Advanced Technology and Information Systems from Johns Hopkins University.

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PARALLEL SESSION 3.2:

EXPLORING THE FRONTIERS OF HEALTH INFORMATION IN A PETABYTE AGE



SOCIAL IMPLICATIONS OF PETABYTE AGE THROUGH EVOLUTION OF MHEATH

MRIDUL CHOWDHURY

THE COMING AGE OF MHEALTH

Earlier telemedicine efforts have mostly been based on computers and laptops, which had some notable challenges, some of which are: 1) The reach of the services was limited, since computers and laptops are not ubiquitous in developing countries; 2) Solutions were expensive and were mostly limited to pilots or benefited the upper echelons of the society. Thus, the benefits of telemedicine were not really democratized.

However, things started changing with increasing proliferation of mobile phones. As these devices have become cheaper and cheaper with more sophisticated features such as Internet capability and application installation capability, telemedicine has taken a wholly new dimension since patient data can now be gathered using the mobile phone. This data can be easily fed into health information systems, thereby opening up the possibility of remote doctor consultation on the one hand, and strategic programmatic interventions by health organizations on the other hand.

WHAT MHEALTH ENABLES IN DEVELOPING COUNTRIES

mHealth enables the possibility of addressing a number of public health problems, some of which are discussed below:

Problem 1: In developing countries, there is a significant dearth of doctors in rural and under-served areas, where doctor absenteeism is a major problem.

m-Health Solution: Link up health workers or junior medical professionals with cell phones which can be used to collect patient information and send to remote doctors for advice

Problem 2: There is a serious lack of access to real-time data needed for strategic intervention by health organizations, such as risk assessment of pregnant women, screening of breast cancer etc.

mHealth Solution: Use the mobile phone to collect real-time patient data through health-workers for health risk screening

Problem 3: Since health-workers are generally huge in numbers, there is also significant costs and resources involved in supervising these health-workers.

mHealth Solution: When the health-workers use themobile phone to submit data, it getsan automatic time-stamp and a geographic stamp through GIS-based systems. The system can also generate automatic SMS alerts to supervisors when health-workers miss pre-scheduled targets thus significantly reducing monitoring costs.

Problem 4: Since health-workers generally get very little medical training, they often have inadequate capacity to remember procedures.

mHealth Solution: The mobile phone based software can have medical triages/ algorithms that can work as a step-by-step guide for the health-workers.

Problem 5: Health awareness information dissemination is quite expensive and is often not need-based, i.e. information is not available at the time people need them.

mHealth Solution: Mobile phone networks can be used for sending out text messages en masse or automated response upon SMS-based request on particular topics.

Problem 6: Patient medical records that can be updated and accessed from anywhere is a critical component.

mHealth Solution: The mobile phone can be used to collect data which if stored systematically in a database creates patient medical records that can be accessed through the Internet from anywhere

SOCIAL IMPLICATIONS OF MHEALTH

Some of the social implications of the above solutions that mHealth can bring are the following:

DEMOCRATIZATION OF HEALTHCARE

Healthcare services are notoriously pronouncely biased towards the rich in most developing countries. With the development of mHealth and a well-developed health information systems, healthcare services can be democratized in a significant way.

EMPOWERMENT OF COMMUNITY HEALTH-WORKERS IN DEVELOPING COUNTRIES

Community health-workers are one of the most significant source of primary healthcare delivery in rural areas of developing countries. mHealth empowers them in a significant way to counter the services of various quack doctors, contributing to social change.

EMPOWERMENT OF CONSUMERS TO TAKE CONTROL OF ONE'S OWN HEALTH

mHealth provides the capability for consumers to collect their own data and send to doctors for remote consultation in certain cases, thus enabling them to take greater control of their health.

EMPOWERMENT OF GOVERNMENTS AND NGOS FOR STRATEGIC AND TIMELY INTERVENTIONS

Through regular collection of strategic health-related data, health organizations in the public and private sectors are empowered to take strategic interventions and prevent emergencies from occurring, thus potentially significantly contributing to maternal and child mortality, for instance.

2020 SCENARIOS OF FRONTIERS OF HEALTH INFORMATION TECHNOLOGY: PERSONAL STATUS MONITORING

JAMES DELLOSTRITTO PRINCIPAL RESEARCHER-CS, BLUE HIGHWAY, SYRACUSE, NY, USA

ALBERT GOLDFAIN, PH.D. RESEARCHER-CS, BLUE HIGHWAY, SYRACUSE, NY, USA

ABSTRACT

In this paper we define personal status monitoring (PSM) and a view of how personalized sensing may be a pivotal catalyst of change in healthcare. PSM is a technology platform intending to provide personal status sensing of physiology, motion, and an individual's immediate environment in an inexpensive and unobtrusive manner, thus providing large amounts of correlated longitudinal data. This is accomplished via sensors that capture data and thus help manage and prevent disease in both developed and developing countries. A shift to personalized care will be the catalysis for the democratization and decentralization of healthcare, and will liberate information for new discoveries. The advent of personal status devices will have lasting changes to the patient-provider relationship as well as provide a wealth of new computable information that can be used by the research community in disease management and discovery.

TRENDS IN THE FRONTIERS OF HEALTHCARE

Longitudinal data in health care is defined as evidence that can be used to assess episodes of illness¹. Today, vital sign devices are one-to-many, costly, and take a single snapshot in time of an individual's health. This snapshot can easily miss the critical transition points in a chronic disease course or during an emergency. Is an irregular and infrequent view of health in the current practice model really effective? PSM is a paradigm shift where an array of vital signs devices are worn in clothing or on the skin for longer periods of time allowing a more comprehensive and personalized view of individual health and disease progression. The availability of the personalized devices will expand our reach providing the ability to monitor those in need in remote under-developed countries and communities. Personalized devices will greatly increase the amount of data and more importantly what can be discovered in that information. There are many exciting efforts all over the world in the development of new cost-effective sensing modalities that will individualize care and bring about the democratization of health care. Personal status sensing is likely the pivotal catalyst for many of the novel techniques in healthcare being discussed by scientists and being implemented by policy writers.

Let us take a moment to speculate on scenarios of care enabled by the advent of pervasive personalized sensing. There are a number of key thematic areas that are linked like a constellation defining a view of the frontiers of healthcare. Each of these themes are linked in a progression of change. The personalization of healthcare is a direct result of efforts like PSM and is the first step acting as the catalyst for the change that will follow. The availability of sensing will help redefine the patient provider relationship as a partnership where the patient owns and controls their health information. A digital health journal on the internet will act as an accessory to your personal health devices. Like a medication is prescribed today, a wearable vital signs device may be prescribed to a patient and worn regularly for disease management or as a screening device over a short duration. Moreover, the prescription of such devices will allow doctors: (1) to monitor patients immediately after discharge, (2) to have a more detailed clinical picture when a new patient is admitted, and, (3) in some cases, to prevent "bounce-back" readmission to hospitals (a costly factor for modern healthcare systems). This device captures a longitudinal and contextsensitive view of health information that can be mined for disease trends or health behaviors aiding in active prevention and diagnosis. There is evidence today that devices like these will be increasingly available in the form of smart band aids and eventually integrated to clothing without requiring adherence to skin.

The second shift will clearly be facilitated by the personalization (first) of healthcare. The democratization (second) of healthcare will be facilitated by the liberation of data in the transfer of ownership of data from sole control of providers to a partnership between provider and patient. Like social networks sharing and controlling access to digital media; so too might health based networks share data captured via the use of inexpensive personal sensing. Like a digital camera on a cell phone used with a social network to share experiences, unobtrusive health sensing devices will be used to share health related data in prevention, disease management, and discovery of new health trends. Democratization of health information mandates a new role for health care providers to vet information sources, collate data, and engage in collaborative decision making with patients². The first wave of change evidence by this movement was witnessed in a self-care trend where patients increasingly used the internet to self-inform, often printing medical references from the internet to share with their providers. The next evolution in the health consumerism movement will expand beyond internet reference and include electronic subjective and electronic vital signs evidence to share with the provider. The patient will take an active role in searching out devices to help in prevention and management of disease or the personal sensor may be administered (just as prescriptions are today) by the provider for any number of reasons including disease management, screenings, and post operative monitoring.

The final shift will start with the democratization of health care and become more profound as personal sensing technology matures to provide higher level clinical grade devices and resultant information in an increasingly mobile fashion. The decentralization (third) of health care has alternate definitions by many authors and researchers. In this context the definition is linked to the personalization or privatization of care where some tasks are transferred from the public to private ownership³. Decentralization is also defined in geographic terms whereby levels of advanced care can be provided in increasingly remote locations reaching those who need care regardless of where they are. There are examples of this today in larger institutions supporting large telemonitoring solutions often connected to very expensive vital signs devices that require institutional support. Inexpensive wearable vital signs will require less institutional support and allow for telemonitoring in small, more efficient, community run institutions and potentially at home.

Wearable vital signs devices are being conceptualized today and will clearly have an effect on healthcare. The personalization of health care via personal status sensing is likely the catalyst for the realization of democratization and decentralization of health care. The arrival of the petabyte age in health care will result from ubiquitous health-data acquisition devices. Above all, these devices will be small and non-invasive, so as to avoid interfering (and indeed, even assist with) the livelihood of their users. These devices will be secure at the point of data collection and beyond, thus ensuring the privacy of their users and the anonymity of health data.

The trend is already turning towards devices that engage their users and provide immediate feedback in a nonclinical, easy-to-

process format. The success of preventive medicine and disease management hinges on our ability to deliver useful feedback to users before they become patients. This will involve applications that summarize health data collected during periods of sleep, exercise, and digestion, and provide an on-demand, lightweight interface to share information with providers and families.

Health data entry used to require a trained user entering the patient data. Lightweight data collection apps for smart phones are combining both sensed and user input data. Both sensed signs and entered symptom data is collected at the point where it is generated, when it is generated, and increasingly, by the person who generated it. A tighter integration with voice-totext software will allow patients with various disabilities and circumstances to provide information to those who need it. The type of data a patient transmits will change as what is currently un-measurable becomes perceivable and guantifiable. This may include radical changes such as the incorporation of patient symptom reports, tone-of-voice analysis, and results of nano-sensing into the pool of vital signs data. The size of specific patient data will be coupled with a continued explosion of high throughput genetic and proteomic data. As our understanding grows about the underlying genetic causes of human disease, we will increasingly need to make devices aware of the genetic and proteomic profile of the patient being measured. With continued improvements in genome wide association studies and microarray data analysis, healthcare providers will know what to expect and what to watch out for. This will help computation by pruning the possible future health states for classification algorithms.

The health record of the future will be the paragon of personalized, patient-first health, but will also be tightly interconnected with other data sources. Imagine an age where the single health record line "family history of high blood pressure" is replaced by generations of actual blood pressure data collected directly from the patient's ancestors. The succinct summary will still be available for presentation to doctors, but it will be expandable into long term longitudinal data to expose the nuances in health patterns. Electronic health records will expose more relevant critical information and prevent costly mistakes.

CLOSING REMARKS

Blue Highway is engaged in an end to end research program in informatics starting at the point of capture in unobtrusive sensing platforms through the entire lifecycle of information and its use in health applications including display, storage, and computation. Our goals are focused on unobtrusive longitudinal personal sensing platforms and the preservation of information diversity and viability for computation intelligence enhancement in a system capable of autonomous adaptation in the light of evolutionary change. This will allow for the preservation of information for use in longitudinal study and great advances in computation intelligence cooperation. At the end of the day we expect to save lives in the discovery of trends that can be detected and corrected.

The personalization of healthcare via unobtrusive longitudinal personal sensing will lead to democratization and decentralization of healthcare and give rise to new discovery. The human condition is something all humans share. Image if we could record this condition over great lengths of time at increasing levels of specificity anywhere in the world. We would likely find it a great source from which to learn. In order to prevent and learn from disease, personal sensing must be pervasive.

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10X 3.2

A VISION FOR ENHANCING PUBLIC HEALTH AND ADDRESSING HEALTH INEQUALITIES THROUGH INFORMATION AND COMMUNICATIONS TECHNOLOGIES (ICT'S)

CHRIS GIBBONS ASSOCIATE DIRECTOR, JOHNS HOPKINS URBAN HEALTH INSTITUTE

Inequalities in health have been documented for hundreds of years. Governments and healthcare systems have been struggling to effectively reduce these differences for decades. Improving public health outcomes and reducing health inequalities has remained elusive for several reasons. First, a growing body of scientific evidence suggests that several sociocultural and environmental factors are important determinants (social determinants) of health and healthcare outcomes. As such many public health experts now agree that poor health results not only from biologic, physiologic and biomolecular processes, but also from complex interactions of social, environmental and behavioral factors which simultaneously and often cooperatively act in concert with traditional 'medical' risk factors to cause disease (1). Inequalities in Health often provide clear illustrations of this truism. For example, in an attempt to eliminate inequalities in health, several early legislative and policy initiatives such as the British Public Health Act of 1848 were created along with State Boards of Health founded in Britain, Germany, France and the US. These exports were designed to improve the quality of drinking water, reduce food related illnesses, reduce pollution, and improve the management of sewage and housing conditions for the poor and working classes. Although significant improvements in longevity and adult mortality did occur after the implementation of these legislative initiatives, problems in many other areas such as infant mortality continued. (1)

In Britain evidence of social inequalities and of inadequate access to healthcare were demonstrated in the mid-1970. In 1980, Sir Douglas Black published a report that analyzed and attempted to explain trends in inequalities in health and suggested policy solutions to address these problems. However, despite policy and legislative action over the next two decades, persistence of health inequalities in Britain were documented in a follow up report in 19973. Finally, in the US, where the healthcare system is often hailed as the "best in the world", significant health inequalities, among individuals with health insurance, have been systematically documented, in many reports, including a widely distributed 2003 report by the US Institute of Medicine. (1)

Given the magnitude and depth of the scientific evidence, it is increasingly clear that a comprehensive understanding of public health and health inequalities will require the integration of knowledge derived from the bench, clinical, sociobehavioral, environmental and population sciences. To complicate public health further, individuals, especially those who are older, often suffer from multiple chronic diseases. They often need home or neighborhood health services, but do not need to be hospitalized. Consequently more family and community residents are becoming "caregivers" and "care providers" This shift is enhancing the impact of social, behavioral, community and economic factors on health outcomes, while at the same time, the world's major healthcare systems are primarily oriented toward acute, hospital based, emergency care. This inevitably results in an inability to systematically reduce health inequalities, effectively address social determinants of healthcare outcomes and consist-ently provide high quality care to all who need it. (2, 3)

Advances in Information and Communications Technologies (ICT) may help overcome these chal-lenges. Recent technology breakthroughs have led to several methodological advances in the biological and molecular sciences (eg, DNA chip technology and microarray analysis), enabled guantum leaps in molecular and submolecular medicine, and catalyzed the emergence of whole new fields of study such as metabolomics and proteomics. In like manner, with advances in ICT's. Public health and the population sciences could realize a similar information and communications technology-based scientific revolution. New ICT solutions may soon permit the real-time integrative utilization of vast amounts of behavioral-, biological-, community and national-level information in ways not previously possible. Behavioral algorithms and decision support tools could facilitate the analysis and interpretation of population data to enable the development of community-wide risk profiles based on population phenotypes (multilevel risk profiles for entire populations) and individual causal profiles (integrative personal risk profiles). This type of integrative, practical and realtime science is the basis of the emerging field of Populomics. The term Populomics has emerged from the synthesis of the Population sciences, Medicine and Informatics (2, 3,4). Populomics is defined as a discipline focused on population level, transdisciplinary, integrative disease/risk characterization, interdiction and mitigation that rely heavily on innovations

in computer and information technologies. Populomics seeks to characterize the interplay of sociobehavioral pathways and biophysiologic and molecular mechanisms which work across levels of existence, to impact health particularly, at the population level. This population-level risk characterization could potentially go beyond the limitations of typical geographic analyses and yield insights distinctly different from risk stratification based on race, socioeconomic status, gender, behavior, urbanization, or biologic factors alone. (2, 4)

The role of technology in public health and inequalities research is not limited to improving our understanding of the etiology and pathogenesis of disease. Technology can also be useful as an interventional agent. While much of the current work on technology opportunities in health and healthcare focus on telemedicine and Electronic Medical Record applications for providers, the field of Consumer Health Informatics (CHI) targets individuals and patients directly and holds significant promise. The potential value of CHI tools and applications is suggested by the rapidly growing numbers of individuals using existing online tools for health purposes. For example, in the US, in little more than a decade, the number of online health seekers has jumped to over 100 million people. The rapid growth in online health activities was fueled in part by significant increases in home broadband and wireless access which in turn enabled many health seekers to engage in much more intense health information seeking activities. Patients indicate that they like the convenience and anonymity of online health information, they have generally been able to find what they are looking for and report that the internet is increasingly helping them to connect to emotional support and practical help for dealing with their health issues. In addition, there has been an increasing interest in wellness activities, information and resources in addition to disease oriented information and resources. (4)

CHI is define as any electronic tool, technology or electronic application that is designed to interact directly with consumers, with or without the presence of a healthcare professional, that provides or uses individualized (personal) information and provides the consumer with individualized assistance, to help the patient better manage their health or healthcare. Recent evidence suggests that CHI applications may be able to reach consumers at a low cost and obviate the need for some activities currently performed by humans. In addition, the data suggest that CHI applications may also be used to enhance the efficacy of interventions currently delivered by humans. Finally the available scientific evidence suggests that CHI applications may hold significant future promise for improving outcomes across a wide variety of diseases and health issues. The evidence appears strongest for CHI applications targeting intermediate outcomes related to smoking cessation. In terms of clinical outcomes, the weight of the evidence appears strongest for the use of CHI applications on mental health outcomes. Because technology can enable the interactive utilization of large amounts of data it has been suggested that Consumer Health informatics applications targeting entire populations (Population Health Technologies) also offer significant promise. (5)

While it is true that inequalities in access and utilization of ICT's exist. The nature of these inequalities is complex, nuanced and multifaceted. Much more research is needed in order for us to go beyond binary characterizations of internet user demographics and attitudes to more completely understand the determinants of utilization, the implications of differential utilization patterns and most importantly, how we can build upon this knowledge to take advantage of the internet revolution to ensure equitable utilization and maximize beneficial health outcomes. (4) The potential extends beyond the US and UK to the entire developing world. According to the United Nations ICT Task Force:

"the ICT revolution can provide powerful new tools both for addressing people's basic needs and for enriching the lives of poor people and communities in unprecedented ways. ...Creating digital opportunities is not something that happens after addressing the "core" development challenges, it is a key component of addressing those challenges in the 21st century.... Development efforts will not realize their full potential if they remain limited to traditional approaches to development and international cooperation."

If we seize upon the opportunities that ICT present for improving health we may one day live in a world where providers and public health officials know and understand how all social, environmental and biological factors collectively contribute to ill health. Health risks may one day be managed before they become diseases and before patients ever need to go to the hospital, Health interventions are delivered via a variety of formats (web, game console, TV, cell phone, in person etc) in a variety of settings (hospital, clinic, home, school etc). The efficacy of traditional Public Health interventions may one day be enhanced via technological adjuncts to care and interventions can be delivered anywhere and at any time, to anybody. In this future world Health information would always
be accessible to every provider, public health worker, caregiver and individual in a form that each understands. In this future world Public Health would become proactive instead of reactive, everyone would have access to care and no one would delay seeking care, because they can get it anytime, anywhere. If we seize upon the opportunities that ICT present for improving health, over time, there exists real potential to make significant impact towards the goal of reducing and eliminating health inequalities and improving Public Health.

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STRATEGIES FOR POSITIVE OUTCOMES: CAN INFORMATION TECHNOLOGY MAKE A DIFFERENCE IN HEALTH IN AFRICA

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ABSTRACT

This chapter looks to the future through the prism of pilot projects well in progress at the time of this writing: use of a malaria electronic tutorial in Mifumi village, development of a mental health electronic tutorial in northern Uganda, and development of an electronic health management system at Tororo Hospital. Each demonstrates a strategy, rooted in African soil, whose ultimate objective is to improve health through IT and medical informatics. The projects connect users, health professionals, and decision-makers, bringing together interdisciplinary teams. These projects all seek to address the question: Can an information and communication technology (ICT) intervention make a difference in morbidity and mortality in African settings? The findings indicate that not only can these interventions be implemented but can be enhanced with community collaboration, making a positive outcome in terms of community adaptation more likely. Finally, this chapter proposes a health informatics center, a Menlo Park for innovation and entrepreneurship in East Africa in which new ICT inventions and interventions for better health can be created from around the region.

1. BACKGROUND

In 1992, a small satellite in a low earth orbit quietly delivered the first electronic version of a medical journal article in sub-Saharan Africa. Published in the New England Journal of Medicine, the article concluded that "treatment with vitamin A reduces morbidity and mortality in measles, and all children with severe measles should be given vitamin A supplements." [1]

At the time, measles persisted as a common killer of children in developing countries, and vitamin A was readily available almost everywhere. Results of this research which had been carried out in Africa, however, had not reached African doctors who could have used it to save lives. The delivery of the medical journal article in sub-Saharan Africa provided a symbolic gesture, bringing home information that had belonged there all along. When the antenna on the ground picked up the signal of the satellite above, it officially brought down the article from the sky to the computer in the ground station in Nairobi.

Mission accomplished, right? Wrong! As difficult as it was to get all the technology to work properly to accomplish this simple exchange, the challenge of access had just begun. The article had been delivered into a void. The technology succeeded - the first electronic delivery of a medical journal article in sub-Saharan Africa - but the transfer of bits, as yet, had no meaning [2].

This small but significant event raises a major question regarding the challenges of using technology to achieve positive outcomes in health.

Today, ubiquitous cell phones in African cities reach even remote areas. On a continent where infrastructures of transport and access to information remain often undependable or unreliable, the cell phone network acts as a superglue keeping people connected – with each other, with the price of coffee beans, or with relatives continents and oceans away.

2. USE OF ELECTRONIC TUTORIALS

2.1 AN ELECTRONIC TUTORIAL ON MALARIA INFORMS PATIENTS IN MIFUMI VILLAGE.

From ivory tower to village health center and back: an interactive tutorial on malaria, combining expertise from the U.S. National Library of Medicine's MedlinePlus with Makerere University Faculty of Medicine in Uganda to focus on tropical disease in developing country contexts. [3]

Nurse Sister Gorretti is a seasoned professional who runs the Health Center in Mifumi village, about 45 minutes along a road through the bush outside of Tororo in Eastern Uganda. She drives to work on a motorcycle. Her approach is caring but no-nonsense, and beneath her unflappable demeanor, one can occasionally catch a glimpse of a warm smile. Gorretti is a remarkable blend of the fortitude and expertise required to run a Center which treats large numbers of mostly women, children, and babies, many with malaria. The surrounding area is highly malarious with water standing in ditches and bogs. Bednets have been distributed in the past with no effect whatsoever on the morbidity and mortality of this major killer of children under five.



FIGURE 1: SISTER GORETTI IN HEALTH CENTER IN MIFUMI VILLAGE. (5089)

Oceans away, the National Library of Medicine (NLM) remains committed to reaching the consumer or end user, no matter what the location of the user, through its popular and widely used database MedlinePlus [4]. In 2005, NLM brought together the existing machine of MedlinePlus with medical school faculty and students at Makerere University Faculty of Medicine, which had recently implemented a case-based curriculum. The challenge was to leverage the delivery platform of MedlinePlus and to work tirelessly with two teams of players from the US and Uganda to reach a successful local outcome that could be shared internationally.

This project creates another layer of health care education in the field and in the medical school, connecting those two worlds in ways whereby each can inform the other. The project leverages existing methodologies such as MedlinePlus and the concept of health information for consumers, to create a new product for an African context, bringing together local health and language experts and a respected university with the cultural context and artists who can reflect that particular context through their use of imagery.

Omusujja gw'ensiri



FIGURE 2. "WHAT IS MALARIA?" A PAGE FROM LUGANDA VERSION OF NLM MEDLINEPLUS AFRICA TUTORIAL ON MALARIA (PPT SLIDE)



FIGURE 3. CULTURAL CONSIDERATIONS IN IMAGE CREATION: IT IS A COMMON BELIEF THAT MANGOES CAUSE MALARIA. (PPT SLIDE)





As the medical students field tested the first tutorial they created on malaria, they witnessed tangible results of their success through the integration of the messages of the tutorial with the life of the village, for example villagers cleaning up areas of their yards which had previously been breeding grounds for mosquitoes. The testing, in turn, increased their desire for working in the field as "agents of change."



FIGURE 5. INSTRUCTION IN THE PREPARATION AND USE OF BEDNETS IN MIFUMI VILLAGE. (3676)

Students, health workers and staffs of clinics can now use the tutorials in both electronic, on computer, CD, or radio, and hard copy formats, as booklet and poster versions, to educate the general public. Through the Community Based Education and Service Program (COBES) at the medical school, students have taken the lead in the distribution of these materials to district health offices, local health centers, youth centers, trading centers, churches, NGOs, and schools in twenty districts.



FIGURE 6. STUDENTS NIXON NIYONZIMA, BRIAN SSERUYOMBYA, AND RONALD KIWEEWA TAKE THE "INFORMATION INTERVENTION"ON MALARIA PREVENTION AND TREATMENT TO MIFUMI VILLAGE. (3590)



FIGURE 7. ARTIST KENNETH NEK WITH MALARIA TUTORIAL POSTERS ON WALL OF MIFUMI HEALTH CENTER (3953)



FIGURE 8. MIFUMI HEALTH WORKER PREPARES TO USE BOOKLETS AND POSTERS IN THE FIELD. (3638)



FIGURE 9. THE AUTHOR WITH A MOTHER IN MUFUMI HEALTH CENTER AS SHE USES THE ELECTRONIC VERSION OF THE TUTORIAL (5065)

Medical students from Makerere University, Moi University in Kenya, and visitors from Israel complete short residencies at the Mifumi Health Center. The project proves to be an innovative way of supporting the enthusiasm of medical students as well as engaging the interest of the people in the village. Makerere medical students have carried out a baseline survey of over 100 respondents on the community's knowledge about malaria. This survey has been analyzed and will be critical in determining whether an information intervention in electronic and hard copy formats can make a difference in the morbidity and mortality of malaria in this community.

IATION SOURCES
you get information about malaria? (can tick more than one) Friends Healthworker Health center Doctor Nurse sister
you ever changed your behavior based on information? If yes, give example. - tes - She forlance such has been forget. - she forlance such has been forget.

FIGURE 10. BASELINE SURVEY OF KNOWLEDGE ABOUT MALARIA IN MIFUMI VILLAGE 2008



FIGURE 11. RONALD KIWEEWA, 4TH YEAR MEDICAL STUDENT AT MAKERERE UNIVERSITY TALKING WITH CHILDREN ABOUT MALARIA PREVENTION IN MIFUMI VILLAGE (3689)

The next phase involves reinforcement of the health message of the tutorial on malaria. At the Health Center, Bernard, a former teacher in charge of community education, and the nursing staff talk daily with the patients when they arrive and take their seats in the waiting area. Bernard uses the posters and bookletstoaidhisconversationsaswellastheelectronicformofthe tutorial with its "crowd puller" images as well as text and audio in local languages. After his demonstration on the computer, the group of mostly women began to use it themselves, pressing the arrow key to advance to the next screen. Further, led by Gorretti and Bernard, the staff and interested patients began a translation of the tutorial into Japadhola, the main local language of this area.



FIGURE 12. WOMEN WITH MALARIA POSTERS IN MIFUMI VILLAGE.



FIGURE 13. BERNARD, USING TUTORIAL BOOKLET, FOR EDUCATIONAL OUTREACH AT MIFUMI HEALTH CENTER. (5025)

In the months ahead, Sister Gorretti and Bernard will continue the malaria education work. Gorretti will also begin to compare the current morbidity and mortality reports she sends to the District Health Office with those from last year. She will take into account the factors other than the information intervention which have informed decreases in malaria. The story is ongoing.

The first two MedlinePlus African tutorials on malaria and diarrhea were developed with the Faculty of Medicine at Makerere University in Uganda. In coordination with the Dean of the Faculty of Medicine, teams from the medical school and NLM worked with African doctors, artists, and medical students to create two original tutorials, as well as guides for their use in the field. The tutorials were field tested as part of the medical students' curriculum and have been translated into local languages of Luganda, Rukiga, Luo, and Japadhola. The project leaders reported that the students enjoyed using the



FIGURE 14. BERNARD GUIDES A PATIENT THROUGH THE MALARIA TUTORIAL. (5044)

tools and were especially pleased to see the community's positive response.

Says Nurse Sister Gorretti: "When we played the CD for them, after that we actually stopped and asked them, have you got any message from what you have just heard, they really say yes. And then when we ask them some few questions that they say the voodoo is not asking, or would not have asked. They say that it helps us to know that they have understood and at the same time they are practicing what they are actually listening to and then whatever was not said from the CD, they request to know from us in detail. Yes....

"Once you see something, then you believe in it more than if you are told. When you physically see something really happening with your own eyes, you learn from it more than when I tell you.

When you see something you really believe in it. And it is very close because it really affects you. You really get it deep in you. It is very possible that you can change behavior from that.....

"They (the patients) were proud that they were learning to do something and they were very happy with what was produced from the screen. A poster they also see and learn from, but from the screen as they were pressing (the arrows), they were also learning, and they felt that they were doing it themselves....

"It is possible that you can change a life. You can make that change to have a better healthy life." [5]



FIGURE 15. SISTER GORRETTI WITH STAFF AND PATIENTS AT MIFUMI HEALTH CENTER. (5101)

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Renata Bushko, Bushko@fhti.org, is director and founder of the Future of Health Technology Institute www.fhti.org, a health technology think-tank dedicated to defining the health technology agenda for the 21st century. Ms. Bushko, after serving on boards of many national US healthcare organizations, international health standards organizations and 15 years as an executive in computer industry, founded Future of Health Technology Institute in 1996. Since then she has chaired fourteen Future of Health Technology Summits. These annual summits engage leading minds from the technology and healthcare fields in envisioning the future of technology for global healthcare to save lives, reduce suffering and extend human potential.

Ms. Bushko is also the editor of Future of Health Technology book series (IOS Press) with its first edition "Future of Health Technology" released worldwide in 2002, second edition "Future of Intelligent and Extelligent Health Environment" in 2005 and "Strategy for the Future of Health" in 2009.

Ms. Bushko holds a Master of Science degree in Electrical Engineering and Computer Science with specialization in intelligent systems from the Massachusetts Institute of Technology (MIT) and a BA in Computer Science from Smith College and University of Warsaw.



MRIDUL CHOWDHURY

CHIEF EXECUTIVE OFFICER CLICK DIAGNOSTICS INC

Mridul has extensive experience in development consulting and technology project management in developing countries. In Bangladesh, he has gained an unique experience in working for all major stakeholders in development – the government, NGO and donor.

Mridul's prior work experience includes co-founding D.Net, an NGO in Bangladesh that has earned international recognition for its work on using information technologies for addressing rural women's health concerns. He has also worked as a Consultant for United Nations Development Program (UNDP) and the Ministry of Planning in Bangladesh in the area of using information technologies for improving governance and enhancing quality of lives of citizens. He was part of the official government delegation from Bangladesh sent to preparatory meetings in Geneva for the World Summit for Information Society (WSIS), a global UN conference on IT policy for social and economic development. During 2001-02, he was a researcher at the Center for International Development at Harvard University, in which capacity he was part of the team behind the first Global IT Report jointly published by Harvard University and World Economic Forum. He has traveled extensively to many developing countries for research and consulting on IT and development issues. He is also a filmmaker, most known for his film titled Deshantori.

Mridul completed an MPA/International Development from Harvard University's Kennedy School of Government as a Dean's Fellow. He has a BS degree with majors in Economics, Mathematics, and Political Science and a minor in Computer Science from University of Texas at Austin.



JAMES DELLOSTRITTO

PRINCIPAL RESEARCHER, R&D BLUE HIGHWAY LLC

With a career mostly rooted in communications, James believes that medical information networks require intelligent network technology supporting true data liquidity. True liquidity will liberate information and allow for the democratization of healthcare whereby patients move freely with their information between providers in a partnershipforprevention and bettermanagement and control of disease. Personalized sensing will provided an increasing amount of data in a cost model providing further reach in developed and developing countries. James has had the unique opportunity within his company to work with others to define research and develop innovative approaches to data liquidity and personal status monitoring across multiple application verticals.

Appointed as Principal Architect at Welch Allyn in 2002, James was charged with the creation of a next generation systems for use in the company on a global scale. The charter of this effort was to define and execute the creation of communications technologies that would enable data liquidity across the entire Welch Allyn product portfolio and system landscape. The program resulted in multiple patents and a center piece component in the Welch Allyn platform.

After more than a decade of accomplishment at Welch Allyn, in 2008 James was appointed as a principal researcher at Blue Highway LLC and continues research in computer sciences for application to medical devices and systems and is the program manager for the personal status monitor program; a low cost wearable monitoring system. James is active graduate student working towards a PhD in the L.C. Smith College of Engineering at Syracuse University. James is the Principal investigator for a sponsored program in adaptive systems with Syracuse University. Additionally, James is the research manager and a contributing researcher for current active research programs with Cornell University, The University of Rochester (U of R), The Rochester Institute of Technology (RIT), and Syracuse University.

GROUPS AND ASSOCIATIONS:

Mr. DelloStritto is a frequent participant in, and contributor to, the Standards Committees and Working Groups relevant to medical devices: data formats, communication, wireless PANs, and remote WANs. He maintains affiliations with the IEEE, AAMI, FHTI Future of Health Technology Inc., CIMIT - Center for Integration of Medicine and Innovative Technology, The Continua Health Alliance serving as the Device Interface Group Chair (2006-2007), Blue Tooth Medical Device Profile Group, and the USB Implementers– Medical Device Interoperability Workgroup.

He is also a distinguished speaker at the Future (ORF) PnP Standardization Program, and a contributing author and member of the Personal Health Devices working group of the IEEE EMBS P11073 Standard committee, and an author on the Bluetooth Personal Health Device Profile.



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Dr. Gibbons is an Associate Director of the Johns Hopkins Urban Health Institute and is on the faculty at the Johns Hopkins' Schools of Medicine and Public Health. Dr. Gibbons' expertise is in the area of Behavioral interventions and Consumer Health informatics where he focuses on using Information and Communications Technologies to improve healthcare disparities.

Dr. Gibbons is a member of the National Academy of Science's Committee on the Role of Human Factors in Home healthcare and has been named a Health Disparities Scholar by the National Center for Minority Health and Health Disparities at the National Institutes of Health. Dr. Gibbon's has recently authored several books including "eHealth Solutions for Healthcare Disparities" and "Handbook of Digital Homecare". Dr. Gibbons is also the author of the Healthcare Disparities Solutions Blog. Dr. Gibbon's work is leading the development of the emerging fields of Populomics, Consumer Health Informatics and Culturally Informed Technology Design.

Dr. Gibbons obtained his medical degree from the University of Alabama. He then completed residency training in Preventive Medicine, a molecular oncology research fellowship and earned a Master of Public Health degree focusing in health promotion among urban and disadvantaged populations all from Johns Hopkins University.



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Gabe Rijpma is the Healthcare and Social Services industry director for Public Sector in Microsoft Asia Pacific. Based in Singapore, Gabe's responsibilities include leading and defining the solution offerings and strategy for meeting the needs of Healthcare and Social Services Customers across Asia Pacific. He also leads collaboration with governments and industry Partners to deliver solutions that help Healthcare and Social Services organizations transform the way they do business.

Prior to assuming his current role in 2006, Gabe spent two years at Microsoft headquarters in Redmond, Washington, United States, as an enterprise solution architect. In that role, he focused on working with customers around the world designing and building systems utilizing service oriented architecture. Gabe started his career at Microsoft in 2000 as a principal technology specialist focused on helping Government Customers realize the value from their technology investments.

Prior to joining Microsoft, Gabe worked as principal consultant at Software Spectrum in Sydney, Australia, where he led the business solutions practice. Before his move to Australia, Gabe was based in Christchurch, New Zealand, where, as an entrepreneur, he was an early pioneer in Internet consulting and Internet business development.

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JULIA ROYALL

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Julia Royall has been working in international health in Africa since 1990 and has more than 30 years of professional experience in the communications field. She has focused her efforts on how access to medical information and the Internet can support improved health, and on the ways in which new technology solutions can assist remote and underserved communities in developing countries. Throughout her career Ms. Royall has been committed to bringing together information and technology with partners, projects, and funding, using a variety of media in US and international settings.

She was recruited to the National Library of Medicine (NLM) at the National Institutes of Health (NIH) in 1997 to create a malaria research communications network (MIMCom) to support scientists in Africa as part of the Multilateral Initiative on Malaria. The first network of its kind, MIMCom comprised 27 research sites in 14 African countries and engaged over 30 partner organizations and institutions in the US, UK, Europe, and Africa. For this work she received the NIH Director's Award of Merit, the NLM Director's Honor Award, and was honored by Federal Computer Week magazine. In 2001, she was made Chief of NLM's Office of International Programs. Focusing on Africa, her program comprises outreach to medical librarians, medical journal editors, researchers, medical students, end users. In addition to new initiatives, she has adapted NLM databases for use in Africa. In 2007-8, she was Fulbright Scholar to Uganda.

Prior to coming to the National Library of Medicine, she was Deputy Director of SatelLife, which created the first telecommunications system for health in Africa. While at SatelLife she initiated and directed the HealthNet Information Service, which served and continues to serve African countries. While a doctoral student at Carnegie Mellon University in 1976, she founded and served as Executive Director of a theatre company which made the history of technology available to a wide array of audiences in local and international settings and was described as a "theatrical child prodigy" and a "total original."

Her research interests include how information technology interventions can make a difference in health in Africa; African American and slave trade history; PanAfricanism; and the relationship between African traditional communication systems, arts, and the Internet. She was Adjunct Faculty at the Johns Hopkins School of Nursing from 2004 to 2007. In addition to her work at NLM, she was seconded part time to the World Bank for an ICT project in Ethiopia.

Prince Mahidol Award Conference 2010

PARALLEL SESSION 3.3:

MEASURING THE UN-MEASURABLE:

DEATH, DISEASE, HEALTH AND HAPPINESS



MEASUREMENT OF HEALTH: WELLBEING PERSPECTIVE

Ronald Colman, Ph.D Executive Director, Genuine Progress Index Atlantic

1. INTRODUCTION: BROADER INDICATORS OF HEALTH AND WELLBEING

Population health analysts have made considerable progress in the last two decades in developing a wide range of comparable indicators of health and wellbeing that go well beyond the conventional disease-based indicators that have dominated health statistics for so long. Non-medical determinants of health now include not only standard behavioural risk factors like smoking, obesity, and physical inactivity, but social, economic, and environmental determinants like income and its distribution, employment, literacy and educational attainment, social supports, criminal victimization, air and water quality, and more.

To give just one example, strong social supports have been shown to be strongly correlated with good health. In fact, social networks may play as important a role in protecting health, buffering against disease, strengthening immunity, increasing compliance with behaviours that promote health, and particularly aiding recovery from illness, as behavioural and lifestyle choices such as quitting smoking, losing weight, and exercising¹. Conversely, lack of social support is linked to higher rates of cardiovascular disease, premature death, depression, and chronic disability².

¹ See for example: Mustard, J.F., & Frank, J. (1991). The Determinants of Health. (CIAR Publication No. 5) Canadian Institute for Advanced Research, Toronto.

² Lyons, Renee, and Lynn Langille, Healthy Lifestyle: Strengthening the Effectiveness of Lifestyle Approaches to Improve Health, Atlantic Health Promotion Research Centre, Dalhousie University, prepared for Health

ACCORDING TO HEALTH CANADA:

"Families and friends provide needed emotional support in times of stress, and help provide the basic prerequisites of health such as food, housing and clothing. The caring and respect that occur in social networks, as well as the resulting sense of well-being, seem to act as a buffer against social problems. Indeed, some experts in the field believe that the health effect of social relationships may be as important as established risk factors such as smoking and high blood pressure³.

In attempting to explain why white American males are five times as likely to die of coronary heart disease as Japanese men, comparative studies have pointed to greater social support and cohesion as a likely explanatory factor:

"The evidence from the Japanese acculturation studies certainly suggests that strong social ties and meaningful social interconnectedness / cohesiveness might be a source of significant protective benefits... and thus be an important factor in the prevention of CHD [coronary heart disease]."⁴

In the past two decades, this growing body of epidemiological evidence has been translated into standard population health survey questions that now serve as the basis for increasingly reliable indicators of the strength and level of social supports. Thus, in Canada for example, Statistics Canada's National Population Health Surveys and Canadian Community Health Surveys have tested social support levels by questions such as whether respondents had someone to confide in, count on in a crisis, count on for advice, and make them feel loved and cared for. Social support was also identified and confirmed as a key non-medical determinant of health by the Canadian Institute for Health Information's National Consensus Conference on Population Health Indicators.,

⁶ Statistics Canada, http://www.statcan.ca/english/freepub/82-221-XIE/00502/defin2.htm#54a

³ Health Canada, Toward a Healthy Future: Second Report on the Health of Canadians, Health Canada and Statistics Canada, September, 1999, page 60.

 ⁴ Kabat-Zinn, Joh, "Psychosocial Factors: Their Importance and Management," in Ockene, Ira, and Judith Ockene, Prevention of Coronary Heart Disease, Little, Brown, and Company, Boston, 1992, pages 301-302.
 ⁵ National Consensus Conference on Population Health Indicators: Final Report, Canadian Institute for Health Information, Ottawa, 1999, pages 5 and B9.

The 2000/01 Canadian Community Health Survey assessed the "level of perceived social support reported by population aged 12 and over, based on their responses to eight questions about having someone to confide in, someone they can count on in a crisis, someone they can count on for advice, and someone with whom they can share worries and concerns."

This is just one example of the wide range of indicators now available that reference the growing epidemiological evidence on the social, economic, and environmental determinants of health. Over the past thirteen years, GPI Atlantic — a Canadian non-profit research institute — has produced more than 100 detailed reports as the basis for a full-blown Genuine Progress Index (or GPI) for the Canadian province of Nova Scotia. This GPI consists of 20 components and several dozen indicators that together constitute what we believe is a reasonably accurate and comprehensive assessment of the wellbeing of Nova Scotians. The 2008 Genuine Progress Index for Nova Scotia is available for free download on the GPI Atlantic website at www.gpiatlantic.org.

In all this work, it must be emphasized that we do not claim or attempt to measure 'happiness' or 'wellbeing' directly. We see all our work as an effort to assess key conditions of wellbeing, based on solid epidemiological and other statistical research that has found high correlations between wellbeing and income, employment, social supports, literacy, air quality, and a wide range of other socio-economic and environmental determinants of health. While these conditions are no guarantee of happiness just as their absence does not guarantee misery, the GPI indicators together certainly enhance opportunities for wellbeing. That is our only claim about our wellbeing indicators.

2. WHY GO BEYOND INDICATORS?

But while the emerging socio-economic and environmental indicators are an essential first step in expanding measures of health and wellbeing beyond conventional disease-based indicators, and thus in helping policy makers assess program effectiveness, they are not enough. Resting on the firm foundation of the indicators, the next necessary step is the

⁷ Statistics Canada, http://www.statcan.ca/english/freepub/ 82-221-XIE/01002/tables/html/2326.htm.

development of a set of wellbeing "accounts" that assess value as comprehensively as the new indicators assess progress.

First, the new population health indicators alone do very little to challenge the economic growth measures (based on changes in GDP) that remain the most powerful national and international influence on policy—for the simple reason that GDP is not an indicator but an accounting system. Not only do population health indicators generally fail to touch the nerve centre of policy, but they also have very limited capacity to change behaviour at the population level— largely because nothing changes people's behaviour like price signals.

For example, all the preaching about greenhouse gas emissions and energy conservation and all the good energy efficiency and climate change indicators in the world did not tempt North Americans to switch away from their gas-guzzling SUVs. But a doubling of oil prices very quickly stopped the SUV lust in its tracks and created an overnight demand for small fuel-efficient cars that the market could not meet. Then it took the economic bubble to burst to dampen the auto craze altogether and remove four million vehicles from American roads.

In fact, all our growing global environmental awareness and activism of the last two decades has not stopped growing global consumption that depletes our natural wealth and resources, and dumps wastes and poisons into our atmosphere at ever more dizzying rates. Sad to say, and despite the pain it will cause, nothing will be better for our natural world than the recent economic downturn—and the deeper the recession the better chance our natural world will have to provide some support for future generations. The economy—nothing else, not our environmental movement, our sustainability charters, our Rio and Johannesburg and Bali conferences, and our best wellbeing indicators—will stop people and businesses and governments from spending and consuming at rates far beyond the capacity of the Earth to support.

And this is equally true for the most obvious and straightforward population health issues. In 2000, Nova Scotia, where I am from, had the highest smoking rates in all of Canada, and all the anti-smoking messages in the world didn't seem to make a difference. But when the government massively increased tobacco taxes, consumption fell like a rock. Within a few years, the rate of teenage smoking dropped from one in three teenagers (33%) to one in five (20%). A simple price signal has saved hundreds of lives and sharply diminished a huge burden of needless suffering.

In short, we won't begin to send price signals that are in accord with health promotion priorities until we change the present produce-and-spend economic accounting system to reflect the true social, health, and environmental costs and benefits of economic activity. And if we do not move from our rather comfortable world of indicators to a much more challenging set of economic accounts and measures of value, we face the real danger that health promotion will remain a wonderfully inspiring set of principles, reflecting people's genuine aspirations—the fodder for countless brilliant speeches in international fora perhaps—but it will become ever more divorced from behaviour and action.

The good news is that the means and methods now exist to create a sane accounting system that not only fully reflects health and wellbeing values but also protects against the boom and bust cycles that our present economic system and its growth-based accounting system inevitably produce. Most importantly—unlike our present winner-take-all-and-future-generations be-damned accounting system—such a new accounting system reflecting true benefits and costs can actually shape an economic infrastructure capable of promoting wellbeing, supporting future generations, and ensuring long-term sustainable wellbeing and prosperity in harmony with the natural world.

The even better news is that It would not take much to start the ball rolling in a new direction. That GDP steamroller is so monstrously unwieldy and primitive that it will quickly stumble and be derailed by a few well-placed accounting tricks. To give just one example, more cigarette and junk food sales make the GDP grow, just as do tobacco and obesity-related illnesses and liposuctions:— How absurd is that from a wellbeing perspective! Is it not simple logic to register the impacts of tobacco as a cost rather than gain to the economy?!

And yet, while it is not difficult to demonstrate the flaws in our predominant GDP-based accounting system — especially perhaps from a health and wellbeing perspective — it is also true that this shift in the economic accounts has to happen quickly for the world and future generations to stand a chance against the juggernaut of endless and excessive consumption that GDP-based accounting promotes.

3. INDICATORS AND ACCOUNTS: WHAT IS THE DIFFERENCE?

To summarize, then, the two kinds of measures required to bring a genuine population health perspective squarely into the policy arena:

1) Population health indicators assess progress and trends in health and wellbeing, and are based on physical measures (e.g. employment, crime, poverty, and physical activity rates, levels of educational attainment, greenhouse gas and air pollutant emissions, etc.) The units of measurement are unique to each indicator, with rates measured in per capita terms (e.g. number of jobs, crimes, smokers, graduates per 100,000 or as percentage of total population). Indicators tell us if things are getting better or worse. And they perform vitally important policy functions, sending early warning signals to policy makers, and assessing which programs are working and which are not in attaining agreed targets.

Accounts assess value, with units of measurement expressed in common monetary terms to the degree possible, and with evidence pointing to economic value when monetization is not possible. Accounts form the basis of government financial incentives and penalties—including taxes, subsidies, and investments in particular sectors of the economy. And those financial incentives and penalties in turn affect price—which, as we saw, is the most immediate, powerful, and effective determinant of behavioural change.

Here are some examples of the difference between indicators and accounts:

Crime rates (an indicator) tell us—in criminal incidents per 100,000 population—whether crime is going up or down, with lower rates signifying progress. Crime rates are now accepted by Statistics Canada as non-medical determinant of health. Accounts tell us the cost of crime to society—how much we spend in dollars on courts, prisons, burglar alarms, security guards, hospital costs due to assault, replacing victim losses, etc. This can be expressed as the amount we would save and have available for more productive investments in wellbeing if there were no crime. We found that crime costs Nova Scotia more than \$700 million a year.⁸

⁸ Pannozzo, Linda, et al. The 2008 Nova Scotia Genuine Progress Index. GPI Atlantic. Halifax. December, 2008. Available at www.gpiatlantic.org.

- Trends in volunteer work can be a good indicator of generosity and community strength, as well as of the social supports that contribute mightily to individual and community health and wellbeing. These trends tell us-in hours-whether volunteerism is increasing or declining. Accounts tell us the economic value of volunteer work-by assessing what it would cost to replace the services presently provided by volunteers for pay. If volunteerism declines, as it has in Canada, accounts tell us the lost economic value of those missing volunteer hours. We found that voluntary work contributes the equivalent of \$1.8 billion a year in services to the Nova Scotia economy⁹. (Of course this figure is invisible in the GDP statistics and conventional economic accounts, which ignore the value of unpaid work and only measure paid work.)
- Smoking rates (an indicator) tell us—in number of smokers as a percentage of total population aged 15 and older whether we are making progress in avoiding the high rates of premature death and illness attributable to smoking. Accounts tell us the cost of smoking to society which, in Nova Scotia, we found was \$171 million a year in direct health care costs and about \$700 million more in lost productivity.¹⁰

Of course, there is a good news side to all these stories. The sharp decline in smoking rates translates into a long-term saving of hundreds of millions of dollars. We calculated that if Nova Scotians didn't smoke, had healthy weights, and exercised regularly, the Province would save half a billion dollars in years in avoided excess health care costs.¹¹

Needless to say, all these examples make very clear the relationship between indicators and accounts, and why the latter depend on the data and evidence provided by the former. It is the change in the rates of smoking, crime, volunteer work, etc, that allow the calculation of the related economic costs and the savings (in dollars) that will accrue from an improvement in the indicator.

⁹ Pannozzo, Linda, et al. The 2008 Nova Scotia Genuine Progress Index.
 GPI Atlantic. Halifax. December, 2008. Available at www.gpiatlantic.org.
 ¹⁰ Ronald Colman and Janet Rhymes, The Cost of Tobacco Use in Nova Scotia. GPI Atlantic. Halifax. August, 2007. Available at http://www.gpiatlantic.org/pdf/health/tobacco/costoftobacco-ns-2007.pdf
 ¹¹ Colman, Ronald, The Cost of Chronic Illness in Nova Scotia. GPI Atlantic.
 Halifax, October, 2002. Available at: http://www.gpiatlantic.org/pdf/health/

 Here is one more example of the relationship between indicators and accounts which scientists tell us will have more profound implications for human health and wellbeing in the long term than almost any other factor. A climate change indicator tells us—in CO2 equivalent kilotonnes whether greenhouse gas emissions are increasing or not and therefore whether we are making progress in combating climate change. Accounts tell us the economic costs of climate change damages and the costs of controlling and reducing greenhouse gas emissions by a certain amount. By comparing those damage costs with those control costs, accounts enable us to assess the cost-effectiveness of particular measures to reduce emissions.

Just that kind of accounting was undertaken recently in the United Kingdom by Lord Nicholas Stern (former chief economist at the World Bank), leading him to conclude: "The benefits of strong, early action on climate change outweigh the costs."¹² Stern found, through actual economic accounting mechanisms, that reducing greenhouse gas emissions sufficiently to stabilise atmospheric GHG concentrations will cost a lot—about 1% of global GDP per year. But he also found that doing nothing will cost the world very much more—the loss of at least 5% of GDP¹³ per year "now and forever" according to the best case scenario of climate change damages. Accounting for all risk factors raised the figure to as high as 20% of GDP. He wrote: "The costs of stabilising the climate are significant but manageable; delay would be dangerous and much more costly."

Until governments actually include the costs of greenhouse gas emissions in their national accounts and annual budgets, actions to reduce such emissions will always be trumped by narrower production and consumption based economic considerations.

 ¹² Government of the United Kingdom, HM Treasury. Stern Review: The Economics of Climate Change: Executive Summary. Available at: http://www.hm-treasury.gov.uk/d/Executive_Summary.pdf. Full report available at: http://www.hm-treasury.gov.uk/6520.htm. Accessed 24 October, 2008.
 ¹³ Atkisson, Alan. Stern Review: How Climate Change is Revolutionizing Economics. World Changing. 31 October, 2006. Available at: http://www.worldchanging.com/archives/005210.html. Accessed 24 October, 2008.

Those few examples illustrate the difference between indicators, which measure progress in physical units of measurement (crime incidents, smoking rates, greenhouse gas emissions, etc.), and accounts which assess value in economic terms. An effective set of health and wellbeing measures requires both, with the former providing the basis of the latter.

4. POLICY IMPACTS

In our Nova Scotia experience, it is our accounts that have had a far greater impact on policy than our indicator work – particularly in influencing health policy. To take just a few examples: It was our GPI assessment that preventable chronic diseases cost Nova Scotia—with its population of less than a million—\$500 million in excess health care costs that led the Province to establish a new Department of Health Promotion with its own budget and its own Minister at the Cabinet table, with the specific purpose of improving the health of the population. The Health Department has effectively become the department of sickness treatment-responsible for hospitals, physician services, and drugs. Indicators like rates of sickness or smoking and obesity could not have had this effect. But when we found that Nova Scotia could save half a billion dollars a year if Nova Scotians didn't smoke, had healthy weights, and exercised regularly, we suddenly had the attention of the Finance Minister, who had never seen health as falling in his jurisdiction.

It is our accounts and economic valuations that have also had far greater influence than our indicator work in promoting very specific health promotion and disease prevention initiatives. For example, cost-benefit analyses indicate that school-based smoking prevention programs can yield a \$15 return in avoided future illness costs for every dollar invested; pre-natal counselling can yield a \$10 benefit; anti-tobacco media campaigns can yield a \$7 benefit; and workplace health promotion interventions can yield a \$2 benefit in reduced absenteeism and other direct productivity benefits for every dollar that employers invest.¹⁴ It is these economic results that also have generated the greatest media publicity and public

¹⁴ Colman, Ronald, The Costs of Tobacco in Nova Scotia. GPI Atlantic. Halifax, October, 2000. Available at: http://www.gpiatlantic.org/pdf/health/tobacco/costoftobacco-ns.pdf; Colman, Ronald, The Cost of Chronic Illness in Nova Scotia. GPI Atlantic. Halifax, October, 2002. Available at: http:// www.gpiatlantic.org/pdf/health/chronic.pdf

interest. For example, a recent GPI analysis estimating the costs of congestion to Halifax yielded front-page newspaper stories, and generated a lively debate on actions to introduce congestion and promote more sustainable transportation modes.¹⁵

And when we found that volunteers contribute \$1.8 billion in services to the Nova Scotia economy annually—more than the combined value of all government services combined—volunteerism was suddenly transformed in the public mind from a fuzzy, warm-hearted, 'feel-good' thing to a powerful contribution to the economy. As a direct result, when the Premier of Nova Scotia presented the annual volunteer-of-the-year awards, the community-based organizations welcomed him to the stage with the presentation of a huge cheque made out for \$1.8 billion, announcing: "Mr. Premier. We are proud to present you with this cheque, which reflects our contribution to the Provincial economy in the past year."

There are many other examples: Our GPI full cost accounting analysis of the costs and benefits of leading-edge solid waste management systems has been used by many jurisdictions as justification for introducing far-reaching recycling and composting programs. Our accounts have assessed the economic benefits of reducing the Province's greenhouse gas and pollutant emissions, the economic impacts of introducing smoke-free workplace legislation, the full costs of motorized transportation in Nova Scotia, the economic benefits of shifts from road to rail freight, the costs of obesity and physical inactivity, and more¹⁶. Remarkably, over 13 years of work in this field, it has become apparent that this accounting and economic valuation work has had far greater ability to shift and influence policy than our parallel indicator work.

¹⁵ Savelson, Aviva et al., The GPI Transportation Accounts: Sustainable Transportation in Halifax Regional Municipality. GPI Atlantic. Halifax. March. 2008. Available at http://www.gpiatlantic.org/pdf/transportation/hrmtransportation.pdf. Sample media clippings available at http://www.gpiatlantic. org/clippings/hrmtransport.htm.

¹⁶ For these and other reports, please see www.gpiatlantic.org.

To conclude, it must be emphasized again that making the case for moving beyond indicators of population health to economic valuations by no means diminishes the importance of the former as the essential base for the latter. And yet — primarily for strategic purposes and as a means of engaging a wider policy audience — I would argue that the next key step in the wellbeing measurement field must be a determined effort to create a set of wellbeing 'accounts' that value population health in economic terms and that count detriments to health and wellbeing as costs rather than gains to the economy.

This notion is unpalatable to many analysts on ethical and other grounds — in part because valuations of human life and health in dollar terms appear to belittle the intrinsic or inherent value of wellbeing. For example, we have heard objections to valuations of voluntary work on the grounds that voluntarism is motivated by care and generosity and is diminished when dollar values are attached to it. And we have particularly heard that economic valuations of ecological services mistakenly imply that such services are replaceable.

Overwhelmingly, however, we have found enormous appreciation that the economic valuations raise the policy profile of vital contributions to health and wellbeing and point to critical values that remain hidden in the conventional economic accounts and measures of progress.

To come back to the specific topic of this Prince Mahidol Award Conference parallel session, titled "Measuring the Un - Measurable" – perhaps the best news is that such measurement is now possible and that formerly 'un-measurable' or 'soft' determinants of health and wellbeing are now eminently measurable. Great advances both in methodology and in data collection and availability in the last 20 years not only enable us to measure trends in health and wellbeing far more comprehensively than ever before, but now enable us to challenge the GDP juggernaut that has contributed mightily to the depletion and degradation of the world's resources and that has too long mistakenly counted detriments to wellbeing as gains to the economy. We now have the means to create a set of health and wellbeing 'accounts' that could revolutionize global health information reporting and systems and even transform our national accounts to include health benefits and costs.

SUMMARY MEASURES OF POPULATION HEALTH

COLIN MATHERS, SOMNATH CHATTERJI, TIMOTHY EVANS

The regular assessment of population health is a key component of the public policy process to improve health levels and reduce health inequalities. With accelerating ageing of populations during the second half of the twentieth century came increasing recognition that it was important to assess not only mortality but also morbidity and disability at the population level. In particular, there was considerable interest in the question of whether populations were becoming more or less healthy as life expectancies increased: an issue referred to as compression or expansion of morbidity (Fries 1980).

Reflecting the rising interest in summary measures of population health in the academic and policy communities, the United States' Institute of Medicine convened a panel on summary measures and published a report that included recommendations to enhance public discussion of the ethical assumptions and value judgements, establish standards, and invest in education and training to promote use of summary measures (Field and Gold 1998). WHO also examined issues around the conceptual, technical, and ethical basis for summary measures of population health and adopted a summary measure (HALE discussed below) to summarize the levels of population health of its Member States. More recently, the European Union has also adopted a summary measure to monitor levels of population health for its members.

The simplest and most widely used method for producing population health statistics is to aggregate data on individuals in order to generate statistics such as the proportion of the population (or of a particular population sub-group) suffering from a given health problem or living in a particular health state, or the number of individuals who die from a particular cause during a specified interval. This approach rapidly becomes unwieldy when a number of problems are being monitored and we want to make comparisons over time, across population groups, or before and after some health intervention.

Summary measures of population health (SMPH) are measures that combine information on mortality and non-fatal health outcomes to represent population health in a single number. Interest in summary measures relates to a range of potential uses. Murray, Salomon and Mathers (Murray, Salomon, and Mathers 2000) identified eight of these:

- Comparing the health of one population to the health of another population.
- Comparing the health of the same population at different points in time.
- Identifying and quantifying overall health inequalities within populations.
- Providing appropriate and balanced attention to the effects of non-fatal health outcomes on overall population health.
- Informing debates on priorities for service delivery and planning.
- Informing debates on priorities for research and development in the health sector.
- Improving professional training curricula in public health.
- Analysing the benefits of health interventions for use in cost-effectiveness analyses.

While such summary measures have many potential uses, they are considerably more complex to calculate, make substantially greater data demands than simpler partial indicators, and have generated considerable controversy for reasons discussed below. This brief paper gives an overview of SMPH, their uses, and the debate around them.

HEALTH EXPECTANCIES

The concept of combining data on health or disability status of populations with mortality data in a lifetable to generate estimates of expected years of life in various health states was first proposed in the 1960s (Sanders 1964; Sullivan 1966) and Disability-free Life Expectancy (DFLE) was calculated for a number of countries during the 1970s and 1980s. A Network for Health Expectancy and the Disability Process, known by its French acronym of REVES, was established in 1989 and promoted the use of health expectancies as summary measures of population health (Robine et al. 2003).

The REVES Network in its early meetings identified the main challenge in the international use of health expectancies was the use of different questions, response scales and concepts (impairment, disability, handicap, quality of life etc) in nationally representative surveys. When a number of cross-national surveys became available in the 1990s, it also became apparent that differences in expectations and norms for health led to lack of comparability across populations in responses to self-report
questions on health and disability.

WHO used a form of health expectancy to estimate the average levels of population health for its member countries in the World Health Report 2000 (WHO 2000). The first HALE calculations attempted to use existing health survey data together with imputed national-level data from the Global Burden of Disease study (see below). The difficulties in comparing self-reported health data across populations, discussed above, severely limited the information input from population-representative surveys. More recent updates of HALE estimates drew on self-report data from the WHO Multi-country Survey Study, rather than national studies, though the improvements in cross-national comparability were limited. Figure 1 shows the estimated HALE, with uncertainty ranges, for 192 WHO Member States in 2002 plotted against GDP per capita.

DISABILITY ADJUSTED LIFE YEARS (DALYS)

While health expectancies provide a potentially useful summary measure of overall levels of population health, combining mortality risks and morbidity or disability information, they do not lend themselves readily to causal decomposition. The Global Burden of Disease study, originally carried out by Chris Murray and Alan Lopez for the World Bank's 1993 World Development Report, developed an alternative summary measure of population health that could be calculated and presented disease by disease (Murray, Lopez, and (eds) 1996; World Bank 2003).

The DALY is a summary measure which combines time lost through premature death and time lived in states of less than optimal health, loosely referred to as "disability". The DALY is a generalization of the well known Potential Years of Life Lost measure (PYLL) to include lost good health. One DALY can be thought of as one lost year of 'healthy' life and the measured disease burden is the gap between a population's health status and that of a normative reference population. DALYs for a specific cause are calculated as the sum of the years of life lost due to premature mortality (YLL) from that cause and the years of healthy life lost due to disability (YLD) for incident cases of the health condition.

Because YLL measure the incident stream of lost years of life due to deaths, an incidence perspective is also taken for the calculation of YLD. To estimate YLD for a particular cause during a particular time period, the number of incident cases in that period is multiplied by the average duration of the disease and a weight factor that reflects the severity of the disease on a scale from 0 (perfect health) to 1 (dead). The health state weights allow time (years of health life) to be used as the common currency for combining nonfatal health states and years of life lost due to mortality. DALYs can thus also be thought of as a particular form of the more general concept of "Quality-Adjusted Life Years" or QALYs, widely used in economic evaluations for health interventions.

Much of the comment and criticism of the original GBD study focussed on the construction of DALYs (Anand and Hanson 1997; Williams 1999) (Arnesen and Nord 1999), particularly the social choices incorporated in it, and relatively little around the uncertainty in the basic descriptive epidemiology, especially in Africa, which is likely to be far more consequential for setting health priorities (Cooper et al. 1998).

Perhaps the most persistent criticisms have come from disability lobby groups and from some health analysts and policy makers, largely in the developed countries, who have seen the quantification of disease burden in terms of disease and injury causes as a retreat to "the medical model of health" and the inclusion of disability in the DALY as implying that people with disability are less valued than people in full health (Mont 2007).

In recent years, WHO has updated the assessment of the global burden of disease for years 2000 to 2004, based on an extensive analysis of mortality data for all regions of the world together with updated inputs from WHO programs and collaborating expert groups for most disease and injury causes (Lopez et al. 2006; World Health Organization 2008; World Health Organization 2009). Figure 2 summarizes regional variations in the burden of disease as measured in DALYs for the year 2004. WHO is currently collaborating with the Institute for Health Metrics and Evaluation, and a number of academic partners, in a comprehensive update of the Global Burden of Disease for the years 1990 and 2005, funded by the Bill and Melinda Gates Foundation (Murray et al. 2007).

ISSUES AND CONTROVERSIES

Summary measures of population health, and the DALY in particular, remain controversial in the international and national health policy arena and in the epidemiological research community. Criticisms of the Global Burden of Disease approach fall into two main groups. First, are a group of critics concerned with the extrapolation of population health estimates where data is limited, uncertain or missing. Second, are a group of critics concerned about a number of issues in the way that the DALY summarizes fatal and non-fatal health outcomes. These two groups of issues are largely separate. The first relate to any attempts to synthesise partial and fragmentary data to provide a comprehensive picture, with particular focus on the data-poor but high mortality regions of the world. The second relate more to social value choices and concepts of health and the degree to which these can be applied universally. This paper briefly discusses this second set of issues.

Some critics have argued against the use of age weights that give lower value to years of life lived in early childhood and older ages and some recent national and international burden of disease studies have used time discounting but not age weights (Jamison et al. 2006; Mathers, Vos, and Stevenson 1999). Murray and others have responded to the criticisms of the value choices made for the original GBD study (Murray and Lopez 2000; Murray and Acharya 1997), but with a shifting interpretation of exactly what it is that disability weights quantify, there is now seen to be much less justification for imposing social values such as age weighting and discounting in a summary measure of loss of health.

A second criticism has been that burden of disease analysis may result in incorrect policy decisions because priorities for health action might be set solely on the basis of the magnitude of burden of disease. Some health economists have taken this concern to such an extreme that they have argued that one should never measure the size of a problem but only the marginal cost-effectiveness of interventions, ie. the health that can be gained for a given expenditure (Mooney, Irwig, and Leeder 1997). In fact, the original GBD study, and the later round of GBD work at WHO, have both been accompanied by a substantial effort in cost-effectiveness analysis, and an explicit recognition that health priority setting requires not only information on the size and causes of health problems, but on the cost-effectiveness of interventions, and on other information relating to equity and social values.

A third area of criticism has related to the methods used to elicit the disability weights with claims that the person trade-off method used in the GBD was unethical, in that it involved hypothetical scenarios trading off saving the lives of people in full health versus saving the lives of people with specified health conditions (Arnesen and Nord 1999). The Global Burden of Disease 2005 study has responded to these criticisms by adopting new valuation methods applied in a number of community surveys currently underway.

The DALYs have received a great deal of criticism from disability advocates. Some of this criticism relates to ethical issues, such as the claim that DALYs devalue the life of disabled persons or that cost-effectiveness analysis imposes an implicit utilitarianism on assessing social preferences. A more fundamental criticism is that the conceptualization of disability found in the DALYs confounds the ideas of "health" and "disability". Many disability advocates in high income countries, justifiably concerned about stigma and social and environmental barriers to full participation in society by people with disabilities, have taken a position that the causes of disability lie in the interaction of the person and the environment, and that people with disabilities are no less healthy than anyone else. In response to these critics, the conceptual basis for the measurement of health and the valuation of health states has been further developed and clarified (Salomon et al. 2003). The DALY is now conceptualized as quantifying loss of health. Thus disability weights should reflect the general population judgments about the 'healthfulness' of defined states, not any judgments of quality of life or the worth of persons.

MEASURING AND QUANTIFYING LOSS OF HEALTH AND DISABILITY

Traditionally, disability has been understood to be the mark of a minority of the population . Prevalence of disability in the population has therefore been determined by what might be called impairment counting: counting those with blindness, deafness, mobility restrictions, disfigurement or deformities, paralysis, mental illness and similar impairments. The justification given for this approach typically is that, intuitively, 'disability' is a matter of serious impairments that affect many or most activities of daily living.

The traditional approach ignores the fact that the experience of disability is highly variable across populations and health conditions. Disability is best understood as a composite of several salient decrements in capacities in functioning associated with a health condition in a range of domains that, together and in different combinations, account for the overall lived experience of disability. Disability then becomes a continuum resulting from the interaction of capacities in multiple domains of functioning with environmental facilitators and barriers. This is the conceptual framework used by the International Classification of Functioning, Disability and Health (ICF) and one that integrates the medical and social models of disability into a single biopsychosocial approach (WHO 2001).

It is possible then to distinguish the capacities of the individual from the impacts (positive and negative) that the environment has in the way that these decrements play out in the actual environment of a person. This separation then allows for appropriate interventions to be directed towards the individual's health condition, the decrements in capacities or in modifying the environment to increase the overall quality of life and well-being of individuals with disability. This approach is the one also taken in the Global Burden of Disease (GBD) study where disability is understood as a decrement in health.

There remain substantially larger variations in reporting of disability across countries than is plausible. Self-reported data contains systematic reporting biases since people understand questions differently and pick categories on an ordered scale based on their experiences and expectations. Attempts at ensuring adequate conceptual translations and uniform understanding of questions and responses do not totally eliminate these problems. Innovative approaches are being explored to address these problems including actual measurements of capacities during health examinations in surveys. However, while these methods demonstrate the existence of biases in self-reported functioning, they have so far not been found to adequately correct for it. These methods will continue to be refined to provide more comparable estimates of disability across populations and over time.

It is probably unfortunate that the term 'disability' was used in the original GBD study since there is so little consensus on the meaning of this term. As used by the GBD and in the DALY it is essentially a synonym for health states of less than full health. To be more precise, the disability weights are intended to quantify functional status of individuals in terms of capacities (as defined in the WHO International Classification of Functioning) in a set of core domains of health such as mobility, affect, pain, cognition etc.

CONCLUSIONS

Global health policy and priority setting in health will be much better served if international health agencies such as WHO and partners continue their effort to fill gaps in population health data collections and improve their quality, and to collate, analyse and synthesise information on population health. The Health Metrics Network is funding health information system capacity building projects in low income countries, as well as providing technical advice and support. There is a strong demand at global and national level for comparable and unbiased information on population health levels and trends -- and summary measures of population health fill one particular set of needs for policy discussions that require a common metric across different priority areas and for high level indicators summarizing trends in levels and inequality in health.

However, very substantial data issues remain. For health expectancies, the problems of measuring and valuing the prevalence of health states in populations in a comparable way remain largely unsolved. For health gap measures such as the DALY, apart from the data gaps for mortality and epidemiological data, there remain considerable difficulties in assessing and valuing the health state distributions associated with specific disease and injury causes.

FIGURES AND TABLES

FIGURE 1: HEALTHY LIFE EXPECTANCY AT BIRTH IN 2002, TOGETHER WITH 95% UNCERTAINTY RANGES, VERSUS GROSS DOMESTIC PRODUCT (GDP) PER CAPITA FOR 2001 IN INTERNATIONAL DOLLARS, FOR 192 WHO MEMBER STATES



GDP per capita (international dollars) in 2001

FIGURE 2: THE BURDEN OF DISEASE, BY BROAD CAUSE GROUP AND REGION, 2004. GROUP I CAUSES INCLUDE INFECTIOUS AND PARASITIC DISEASES, PERINATAL, MATERNAL AND NUTRITIONAL CONDITIONS. GROUP II COMPRISES NONCOMMUNICABLE DISEASES AND GROUP III, INJURIES.



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MAKING INDICATOR COUNT: THAILAND INITIATIVE ON THE NATIONAL PROGRESS INDEX [NPI]

APIRAK KOSAYODHIN ADVISOR TO THE PRIME MINISTER

Thailand is one among the global communities that has been increasingly aware of the issue of sustainability and the appropriate development pathway which need to be urgently addressed and changed. In past decades, the country has generally performed well in the economic dimension with impressive GDP growth of almost two digits in many years. But yet it inevitably came with the invaluable cost to society and the environment as a whole and more importantly many people even argued whether that growth would actually bring about people well-being.

Our past studies on the development of measuring progress of the country beyond GDP have come up with many lessons learnt and strategic conclusion as follows;

- 1. Technically and academically, Thailand has already developed several indexes for charting the society progress in the last decade, for instance the social index [NESDB], the happiness index [academic institution and NGOs], the quality-of-life index [Ministry of Social Development and Human Security] etc. However, none of them could really reflect the overall picture of the national progress since most of them were developed by each organization with specific purpose. For that reason, the index was seen as the organization's task or goal [ends] rather than being the development tool [means] of the society towards the goal of national progress as intended.
- 2. There are three main conditions that are the factors contributing to the success of the development of indices. Firstly, the ownership and sense of belonging of the index across the society. Secondly, the continuity of the execution process of the index in all levels and in different dimensions. Thirdly, the linkage between the national statistic system [the national account of well-being] and the decision-making process. These three are critical success factors that have not been addressed in the past. The main efforts mainly went to the development of new index instead of paying attention to ensuring successful implementation.

3. The National Economic and Social Development Board (NESDB) has developed a very comprehensive society well-being index [SWI] with active people participation process. The SWI consists of six domains and fifty one indicators, covering almost all dimensions used in the international progress index. Sixteen public forums have been launched during the index development process. However, challenges remain in making the index recognized and utilized both in government and the society.

The government has realized the importance of having an index to measure the progress of the country beyond GDP and to have it implemented. Thus, the ThaiHealth Promotion Foundation Board, chaired by the Prime Minister, has planned to launch the 3-year National Initiative Programme for supporting the movement. The programme will emphasize not only the development of the index but also the social movement of the society for making the index count. So far, there are progresses of the initiative as follows;

- The conceptual framework of the national progress index [NPI] has been strategically re-analyzed and drafted both in term of its content [definition, domain of progress and indicators] and also the presentation of progress measurement to the public. The NPI would be derived from the SWI of NESDB [the national account of well-being] with the complementary elements of subjective well-being dimension and the public opinion regarding what people meant about "PROGRESS". The NPI will be mission-based and outcome-oriented in its nature, thus the selection criteria will put priority on (1) people relevancy or desired goal of the society and (2) public policy linkage rather than mere government statistics like in the past.
- The national campaign of "TURNING POINT THAILAND" has been prepared to be launched in the second quarter of this year [Thailand New Year] to raise awareness and create ownership among Thai people and public media.
- The innovative mechanism called "the NATIONAL TASK FORCE" has been set for supporting the culture of evidence-based public policy and decision-making process. The NATIONAL TASK FORCE will consist of all sectors including government authority, academic institution and civil society; for instance NESDB, National Statistics Office, National Health Committee, University network etc. The working group will work independently but closely with the government agencies. It would function as the society

think-and-do tank for initiating the progress markers toward the national outcome challenges [set in NPI] and provide practical and innovative options for reaching them by all sectors in the society not the government alone.

MEASURING THE IMMEASURABLE: BHUTAN'S EXPERIMENT WITH MEASURING GROSS NATIONAL HAPPINESS

DORJI PENJORE THE CENTRE FOR BHUTAN STUDIES, THIMPHU.

Both Thailand and Bhutan are fortunate in having enlightened monarchs. It is without coincidence that profound development concepts like 'Sufficiency Economy' in Thailand and 'Gross National Happiness' in Bhutan should originate from their respective kings, not social scientists or philosophers.

GNH was born out of a vision that the ultimate purpose of any human endeavour, governance or development should be to increase happiness or wellbeing. This is indeed a fundamental universal value in every society, but is being challenged by dramatic changes in our society. Ever since his coronation in 1974, the Fourth King of Bhutan has made happiness the centrepiece of his reign. "Gross National Happiness is more important than Gross Domestic Product" is distillation of his vision for Bhutan in relation to global changes.

GNH was purely a domestic affair until the current Prime Minister of Bhutan presented it at the United Nations Millennium Meeting for Asia and the Pacific in 1998 and explained it in terms of four pillars: (1) equitable and balanced socio-economic development; (2) preservation of culture; (3) conservation of natural environment; and (4) promotion of good governance. These pillars are indeed the four priority areas of the government's development programme started in the 1960s.

Following the government's directive to make GNH systematic, the Centre for Bhutan Studies has conducted the national GNH survey (2007-2008) for the purpose of developing GNH Index and practical and target-oriented GNH indicators for adoption by the government as a measure of development. The survey was based around nine domains 1) living standard, 2) ecological diversity and resilience, 3) culture diversity, 4) good governance, (which are four pillar equivalents), 5) community vitality, 6) time use, 7) health, 8) education, and 9) psychological wellbeing. It was preceded by a pilot survey in 2007.

Although GNH is a complex concept and ideal, for practical application, GNH philosophy had to be translated into a metric system. The government expressed the need for

GNH indicators because without some kind of measurement system, GNH cannot guide practical policies and programmes. Left at the level of inspirational discourse, imprecision will allow many conventional indicators to play unwitting roles in a GNH society. GNH indicators include both objective and subjective dimensions of life. The construction of an index should give equal weight to both the functional aspects of human society as well as the emotive side of human experience. To give just one example, people's perceptions of their own safety and security are as important in determining happiness as objective crime statistics. That balance allows good representation of information between the objective and the subjective.

A single digit GNH index can be broken down into individual component indicators that are useful for different sectors for planning and technical purposes at the ministerial and departmental levels. The GNH Index was developed to serve as a benchmark for pursuing holistic developmental goals over and above any of the conventional indicators, and to serve as indicators for guiding development priorities in terms of resource allocations in the 10th and subsequent plans. The purpose of the GNH index is to reflect GNH values, set benchmarks, and track policies and performances of the country. A single digit GNH index can be broken down into individual component indicators that are useful for different sectors for planning and technical purposes at the ministerial and departmental levels.

To operationalise GNH, the Planning Commission was reconstituted and named GNH Commission in 2008 as the apex strategic body to define the structures and processes of decision-making unique to a GNH state. GNH committees are being formed at the ministry, districts and gewog levels. These institutions and processes will forge stronger and clearer links between concepts of GNH and their application to policy and programme formulation, and help shape the nature of political economy, legal foundation, health and education systems, and so forth, much more distinctively in the course of time.

Good indicators are useful only if they are used for informing public policies and projects. The Centre has developed a set of tools for selecting pro-GNH policies and projects, and thereby operationalize GNH or integrate GNH indicators into planning, policies and projects. These tools will provide a systematic appraisal of the potential effects of proposed policies and projects on GNH of the population based on key determinants of GNH identified by the national survey. Government ministries and sectors are required to consider all relevant GNH dimensions while formulating the public policies and projects so that the negative impacts are minimised, and, consequently, support a holistic approach to policy development and project implementation. It will also force sectors to acknowledge potential negative impacts of their policies and projects and penalizes them accordingly. The policy and project selection tools not only break the narrow sector walls, but forces them to acknowledge unintended negative consequences of their policies and projects on GNH.

The national workshop was held in December 2009 to infuse education system with GNH values and principles deeply and fully; identify elements of GNH that can be transmitted through core and extra-curricular activities at different levels; work out strategies; improve quality and content of education; and to make education "holistic, contemplative, eco-literate, culturally-responsive, and creative thinking". In June 2009, the Centre for Bhutan Studies national storytelling conferences to recognize, revive, and promote rich oral traditions, especially in the urban areas. The first National Gross National Happiness Survey, 2007-2008 revealed that 96.3 percent of respondents considered folktales as important.

One perceived limitation of GNH in terms of cross cultural application is strong influence of Buddhist values. That Bhutan's GNH indicators have a lot of Buddhist values is purely accidental since Buddhism happens to be our religion. Those Buddhist values can be replaced by compatible or equivalent values fundamental to and promulgated by other faiths. One good example of implementation of GNH is Brazil, a strong Catholic country and they faced no problem in adapting it to the local context.

GNH is a holistic development concept which takes into accounts both the material and spiritual aspects of development. It gives equal importance to all forms of capital – human, natural, cultural, economical, and social capitals. It tries to dislodge reductionist worldview with a holistic worldview of interdependence, networks and relations. Indicators of all nine domains are related to each other in influencing individual and collective wellbeing. Nine domains are mix of both conventional domains like health, education, living standard, ecology and good governance, while four are non-conventional domains neglected in most countries, namely, psychological wellbeing, work and leisure, culture, and community vitality.



RONALD COLMAN EXECUTIVE DIRECTOR GENUINE PROGRESS INDEX FOR ATLANTIC CANADA (GPI ATLANTIC)

Dr. Ronald Colman is founder and executive director of GPI Atlantic, a non-profit research group that has constructed an index of wellbeing and sustainable development called the Genuine Progress Index (GPI), using the Canadian province of Nova Scotia as its testing ground. The GPI is a response to narrow measures like Gross Domestic Product, which record ecological destruction, sickness, natural disasters, and other detriments to wellbeing as economic gains. The Nova Scotia GPI is one of the world's most comprehensive attempts to supply better and more accurate measures of wellbeing to a government to guide its legislative decisions, using a wide range of social, economic, health, and environmental indicators and economic valuations that receive inadequate recognition from mainstream economists.

Ron was born in Australia in 1947. A political scientist, he taught in universities for nearly two decades. He moved to Nova Scotia from Colorado in 1990 to teach international politics, political theory and philosophy at Saint Mary's University. He has also worked as a researcher and speech-writer at the United Nations.

Ron's career took a drastic turn after he read an October 1995 article in the Atlantic Monthly called "If the GDP is Up, Why is America Down?" It explored how progress is conventionally measured in items bought and sold rather than in terms of ecological and human health and happiness. Ron started a research project based on that article for his final year students, which eventually became GPI Atlantic. He guit his university job in 1997 in order to work full-time on the GPI, and has since authored and co-authored numerous reports on measures of population health, social wellbeing, natural resource health, and environmental guality. In 2001 Ron co-authored the first comprehensive report measuring Nova Scotia's ecological footprint. From 2000 to 2003 Ron sat on the sustainable development indicators steering committee of the National Round Table on the Environment and the Economy. He also served as editor of the national magazine, Reality Check: The Canadian Review of Wellbeing, from 2001 to 2005, and was research director of the Canadian Index of Wellbeing. In 2005 he and GPI Atlantic hosted the Second International Conference on Gross National Happiness, attended by 450 delegates from 33 countries, including the present Prime Minister, Education Minister, Health Minister, and delegation of 21 senior officials from Bhutan, and some of the world's leading experts on development that effectively joins social, economic, cultural and environmental objectives. Ron travels extensively to present the GPI work to the public and media, and advise governments, universities, and communities on indicator and economic valuation work. He also works closely with the Royal Government of Bhutan, which has adopted Gross National Happiness (rather than Gross National Product) as its central policy goal. In December 2009 he assembled progressive educators from around the world for an international workshop in Thimphu, Bhutan, on "Educating for Gross National Happiness."

For further information on the Nova Scotia Genuine Progress Index and reports authored by Ron, please visit http://www.gpiatlantic.org/ publications/gpipapers.htm. For a 7-minute video interview on the GPI, please visit www.gpiatlantic.org, and for a recent interview, please see The Economics of Happiness, by John DeMont (2009): http://www.saltscapes.com/component/option,com_kunena/Itemid,31/catid,5/func,view/id,58/



TIMOTHY EVANS

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Dr Tim Evans, of Canada, is currently the Assistant Director-General for Information, Evidence and Research. From 2003 to 2007, Dr Evans served as the Assistant Director-General for Evidence and Information for Policy. He has a Bachelor of Social Sciences from the University of Ottawa and a D.Phil in Agricultural Economics from the University of Oxford, as well as a Doctor of Medicine from McMaster University in Canada.

Dr Evans trained in internal medicine at the Brigham and Women's Hospital at Harvard University. He was an assistant professor of international health economics at the Harvard School of Public Health. From 1997-2003, Dr Evans was Director of Health Equity at the Rockefeller Foundation.



LARAGH GOLLOGLY

MANAGING EDITOR BULLETIN OF THE WORLD HEALTH ORGANIZATION

Dr Laragh Gollogly is currently managing editor of the Bulletin of the World Health Organization, in Geneva, Switzerland. She was previously senior editor at the Lancet, a position that she initially held during clinical training at the John Radcliffe Hospital in Oxford. She has a MD from the University of Liège in Belgium, and an MPH from James Cook University, Australia. At the World Health Organization, she divides her time between ad hoc monographs, publishing policy, communications for the cluster of Information, Evidence and Research, and co-chairing WHO's Guideline Review Committee.

APIRAK KOSAYODHIN

ADVISOR TO PRIME MINISTER OF THAILAND

Mr. Apirak Kosayodhin, Advisor to Prime Minister of Thailand and Chairman of Asian Knowledge Institute (AKI), has been recognized as one of Thailand's most outstanding and experienced executives in both private and public sectors.

Born in Bangkok on 30 March 1961, Mr. Apirak graduated with a Bachelor Degree in Food Science and Technology from Chiang Mai University in 1983, a Master's degree of Business Administration in Marketing from the National Institute of Development Administration (NIDA) in 1986, and a Certificate in Advanced Management Program (AMP) from Harvard BusinessSchool, U.S.A. in 1997. In 2007, Mr. Apirak was granted an honorary doctoral degree in Public Management by Kasem Bundit University in Bangkok.

Began his working life at Pizza Hut as Assistant Manager, Mr. Apirak went on to become a Director of Sales and Marketing of Pepsi-Cola International, Southeast Asia. Because of his leadership and management skills, in 1994 he was appointed the first Managing Director to start up and successfully run Frito-Lay business, a subsidiary of PepsiCo Inc., in Thailand. In 2000, he joined GMM Grammy Public Company Limited, a leading media and entertainment conglomerate, as President and Chief Executive Officer; and in 2002, he entered highly competitive telecommunication industry by taking up a post as Chief Executive Officer of TA Orange Company Limited, one of the largest telecommunication firms in Thailand.

Mr. Apirak was not only a skilled executive in business, but he was also active in working with several public organizations. He was appointed a Board of Director of the Stock Exchange of Thailand and the President of the Marketing Association of Thailand in 2002. He used to be a Committee member for Promotion of Educational Standards and Quality Assurance of the Office of National Education Commission and a lecturer for business and political leadership courses in many renowned institutions.

Following his political will and social minded, in 2004 Mr. Apirak resigned from his post at TA Orange to run for the Governor of Bangkok as a candidate from Democrat Party. After being elected by popular vote of more than 900 thousands of eligible Bangkok voters in August 2004, Mr. Apirak became the youngest and the first Governor of Bangkok who came from private sector. During his tenure, Mr. Apirak successfully launched several important projects to improve the quality of life for the city people including mass transit system (BTS), climate change, education, and urban planning and development. On international aspects, he actively promoted city cooperation to strengthen relationships and to exchange ideas and developments between Bangkok and major cities around the world, namely : Bejing, Chao-Zhou, Seoul, Fukuoka, Liverpool, Washington D.C., Brisbane, etc. Mr. Apirak has also been well regarded as honorary speaker in several world seminars such as The ASEAN 100 Leadership Forum 2005 in Singapore and 2007 in Vietnam, and the C40 Cities Climate Summit in New York.

After completing his 4-year-term with remarkable experiences, dedication, and considerable developments in many areas, Mr. Apirak was reelected on the second term as Bangkok Governor with nearly 1 million votes.

Currently, Mr. Apirak serves as Advisor to the Prime Minister of the Kingdom of Thailand, Mr. Abhisit Vejjajiva, overseeing the economic policy to set Thailand strategy roadmap for the development and competitiveness of the nation. On another role, Mr. Apirak is the founder and Chairman of Asian Knowledge Institute (AKI), a social enterprise which aimed to be the hub of diversified Asian knowledge, talent, and skills to drive global business forward and to create the leadership blueprint for the new era.

Mr. Apirak is married to Mrs. Patima Kosayodhin; and they have a son, Anak Kosayodhin.



DORJI PENJORE

DEPUTY DIRECTOR CENTRE FOR BHUTAN STUDIES BHUTAN

Mr Dorji Penjore is a senior researcher at the Centre for Bhutan Studies, a government think-tank primarily responsible for studying Gross National Happiness (GNH), measuring GNH through national surveys, constructing GNH index and indicators, developing GNH project and policy selection tools for different sectors, and initiating a host of many other activities for integrating GNH into public policy and programmes. He studied anthropology at the Australian National University, Canberra.

PARALLEL SESSION 3.4:

HARMONIZING MULTIPLE HEALTH INFORMATION SYSTEMS THROUGH EFFECTIVE SYSTEM ANALYSIS AND DESIGN



eHEALTH IN HONG KONG

NGAI TSEUNG CHEUNG

INTRODUCTION

Hong Kong has 43 public hospitals and 12 private hospitals that serve a population of 6.83 million people with 25 million visitors to the country per year. It boasts one of the world's lowest infant mortality rates and longest life expectancies.

Hong Kong spends five and a half percent of its GDP on healthcare; 57 percent in the public sector and 43 percent in the private sector. [1] Public funding is governed by the Food and Health Bureau (FHB), one of 11 public bureaus responsible for public policies. Within the FHB, the Department of Health oversees public health measures and the Hospital Authority (HA) manages all public hospitals and government outpatient clinics.

The HA was formed in 1990 to manage all public healthcare services including 43 public hospitals/institutions, 47 specialty outpatient clinics and 74 general outpatient clinics. The public sector has a total of 27,742 hospital beds and 29,000 clinical staff delivering over one million inpatient visits, two million emergency visits and 13 million outpatient visits annually. One hundred percent of long-term care, 93 percent of inpatient and tertiary care and 24 percent of primary care are provided by the HA with the balance provided by the private sector.

COMPUTERIZED PATIENT RECORDS SYSTEMS

HA first developed its IT infrastructure in 1991, including financial, human resources, patient administrative and departmental systems. In 1994, it began developing its Clinical Management System (CMS), an integrated computerized patient record system that gives clinicians access to all available electronic clinical information on their patients. HA adopted a centralized approach in developing its CMS for clinical care, greatly reducing IT cost per hospital. Inter-operability between different hospitals was one of the key aims in developing the clinical management system. Thus, in Hong Kong, 160 facilities in the public sector use the same CMS. The system has a familiar user interface to enhance the efficiency in a busy clinic setting. The HA CMS has very high user acceptance and is in use in everyday care delivery.[2]. HA's Electronic Patient Record (ePR) was first developed in 2000 using a unified

information model [3]. It provides a standardized repository of all clinical data collected throughout the HA and offers a clinician-friendly view into the comprehensive longitudinal lifelong record of the patient. In addition, the ePR acts as a data source for clinical decision support, and a rich resource for audits, research and reporting. The ePR is comprehensive in scope and includes details of patient episodes and visits, diagnoses, procedures, discharge summaries, allergies and alerts, all medications, laboratory and radiology results, nursing and allied health information, documents and letters and specialist clinical data. In recent years, radiological images have also been available throughout the HA as part of the ePR and patients can also elect to share their health record with clinicians outside the HA. As of 2007, eight million patient records are held in the ePR.

Hospitals and clinics	164	CMS transactions	8 Million daily
Visits	15 Million	ePR transactions	700,000 daily
Inpatient admissions	over 1 Million	X-ray images	70 Million
No of patient records	9 Million	Laboratory items	900 Million
		Prescription items	340 Million

The CMS and ePR are integrated across all settings throughout HA facilities including emergency, inpatient, outpatient and outreach services. CMS and EPR are essential clinical and management tools for Hong Kong and, together, handle over three million clinical transactions per day.

Computerization in the private healthcare sectors is less developed. Although most of the 12 private hospitals have financial and administrative systems, CPOE and clinical documentation are still in their infancy. In the ambulatory sector, only 20 percent of the 5,000 private practitioners use computerized patient records systems.

RECORDS SHARING PILOT: PPI-EPR SHARING

The PPI-ePR sharing project was established in 2006 as the first large-scale feasibility test for sharing patient records between public and private healthcare sectors. After receiving patient consent, clinical records are shared with participating clinicians through an Internet portal. The patient is assigned a PIN (personal identification number) and his ePR record is then extracted and encrypted into the secure PPI-ePR database.



FIGURE 1. PPI-EPR PROJECT

Physicians in the private sector who participate in this project are also given a PIN and a security token in which a six-digit number is refreshed each minute. The physician uses his PIN and token number, combined with the patient's Hong Kong identity number and PIN, to access the patient's record. Upon successful authentication the PPI-ePR will display the patient's record on the Web browser, protected by SSL-VPN. As an additional security measure, an SMS message will be sent to the patient's mobile phone, alerting him of the physician's access to his record. [5]

As at December 2009, a total of 12 private hospitals, 10 private or non-governmental organizations providing healthcare services, including over 40 residential care homes, have joined the pilot project. A total of 81,500 patients and 1,378 private healthcare providers have enrolled in the project.

RADIOLOGICAL IMAGE SHARING FROM PRIVATE SECTOR

The Radiology Image Sharing is a second records sharing project which allows private radiology facilities to transfer electronically the diagnostic images and radiology report of the patients referred by HA and make them available in HA CMS / ePR. Under this scheme when a patient is referred to a private sector radiologist their radiological image will be transferred back to the HA in DICOM III format while the report will be sent in pdf format and data in HL7 format. The image and report will be incorporated into the HA's ePR.

GOVERNANCE

The HA has instituted formal clinical IT governance structures and processes [4] in which the public hospitals and more than 220 clinicians from all specialties are engaged in the design, development and implementation of the clinical systems. This emphasis on clinician engagement and ownership has achieved high utilization rates and produced real clinical and business benefits. In addition, strong portfolio management with control of scoping and prioritization has led to a very cost effective program. To date, the HA has spent \$200 million U.S. on the development and implementation of this clinical informatics portfolio. For future development, the HA has established "Clinical Systems Strategy 2007-2012", a Phase III program of the CMS that will extend the benefits of e-health to the private sector.

In recent years, several government papers and reports have highlighted the need to extend patient record sharing beyond that which has already been achieved within the HA, so that patient records (with patient consent) can flow freely between different care settings in both the public and private sectors. To accomplish this goal, the Food and Health Bureau established a steering committee on E-Health Record Sharing and in July 2009 secured \$702M in funding to develop the Hong Kong wide electronic record sharing infrastructure. An eHR Office (eHRO) has been established to plan, develop, implement and manage the eHR program and system development and to handle various policy and legal issues including data privacy and security arising from the system

Six guiding principles have been proposed for the development and operations of the HK-wide EHR:

Record sharing should be compelling but not compulsory, and patients will be in control of the sharing of their record.

The model would be a Government-led program with capital funding supported by the government.

Privacy and security are of paramount importance.

Open technical standards should be employed.

A "building block" approach should be employed.

The program should leverage the existing expertise and experience gained through the development and deployment of CMS & ePR in the HA

STANDARDS DEVELOPMENT

In order to ensure interoperability amongst the different electronic record systems in Hong Kong and the EHR the EHR Information Standards Office has been created and a comprehensive eHR Information Standards Governance structure has been established.





International standards will be used where possible with clear processes for local extension. A phased approach will be taken to the implementation of the standards.



eHR Governance

ELECTRONIC HEALTH RECORD ENGAGEMENT INITIATIVES (EEI) PROGRAM

The participation of all healthcare sectors is essential to building a successful territory-wide eHR system and the Electronic Health Record Engagement Initiative (EEI) was launched in 2009 to engage the private and NGO healthcare sectors at an early stage of eHR development. The EEI invited expression of interest from all potential healthcare stakeholders by submitting proposals on possible partnerships for eHR development. As of December 2009 with 54 proposals had received from almost all the major stakeholders or representative organizations.

WAY FORWARD

The EHR Project Management Office has already been established to undertake the design and development of the EHR sharing infrastructure, as well as to adapt the HA CMS or other EMR technologies for use by the private sector. The first phase of the EHR project will be completed in 2013/14, and will deliver a standardized, longitudinal, patient-centered, Hong Kong wide electronic health record for all citizens of Hong Kong.

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CURRENT INITIATIVES IN DEVELOPING COUNTRIES - FEEDBACK FROM TECHNICAL BRIEFING

DR CHRIS SEEBREGTS

SUMMARY

The International Development Research Center (IDRC) and Rockefeller Foundation have jointly funded a project to develop an open Health Enterprise Architecture (EA) Framework (HEAF) for developing countries. The aim of the HEAF project is to use EA methodology to improve and harmonize eHealth and health information systems design and leverage advances in health information systems strengthening from both developed and developing countries. The HEAF project includes technical reference implementations in several African countries as well as development of system building blocks and aspects of EA framework specification. A Technical Briefing on the HEAF project will take place at a side meeting of the Prince Mahidol Award Conference where members of the global consortium will discuss key features of the project, related to harmonizing approaches to standards and architecture, health requirements definition and health informatics support and reference country implementations. The purpose of this presentation will be to report back on outcomes of the technical briefing and progress on the reference country implementations.

BACKGROUND

The majority of existing developing country health information systems provide unreliable data and significant efforts are required to improve health information systems (HIS) in resource-constrained settings ... Many countries know little about their leading causes of death and are ill equipped to take advantage of the efficiencies and other benefits offered by modern information and computer technology. Existing information systems are mostly implemented in isolation with little consideration of issues such as interoperability and alignment against a national design. Methods that help improve the design aspect of health information systems implementation, by developing methodologies and building blocks that are able to address these issues, will potentially assist countries harmonize existing systems and potentially leverage existing and new HIS implementations. In July 2008, the Rockefeller Foundation organized a four-week Conference on eHealth in Bellagio, Italy. At the Conference, there was general agreement among participants of the session devoted to Interoperability that Global South (GS) countries urgently need an architectural framework and 'maturity model' against which to design eHealth systems, plan implementations, make build-or-buy decisions, decide on acquisitions, evaluate education and training needs etc. The Bellagio eHealth Call to Action document launched on 12 November 2008 urges concrete actions towards the construction of better health systems for all, especially for the GS. It was also agreed by participants that a unique window of opportunity exists to respond to this challenge and introduce a coordinated architectural approach for implementation at a country level before a combinatorial explosion of uncoordinated systems makes this alignment impractical or extremely expensive to implement.

Several initiatives have already started to address this issue, including the Health Metrics Network Architecture for National Health Information Systems and the Open Architectures, Standards and Information System for healthcare in developing countries (OASIS) project. The open Health Enterprise Architecture Framework (HEAF) project is an elaboration of these existing initiatives and a response to the Rockefeller Foundation Call to Action.

POTENTIAL PROJECT BENEFITS

There are several potential benefits that can result from adopting an open enterprise architectural approach. Systems can be coordinated and designed in such a way that economies of scale are realized. Common paradigms or 'architectural patterns' can be used as common metaphors that allow the knowledge gained from one implementation to be used in another. Perhaps most importantly, open e-Health architecture can help countries maximize investment from systems developed by the plethora of in-country organizations, donors, NGOs etc.

An open enterprise e-Health architectural framework has the potential to offer a generalized methodology and suite of tools that can be used by many countries following customization. This has substantial benefits in terms of lowering the cost and risk associated with de novo implementations and 'reinventing the wheel'. An open enterprise e-Health architectural framework has the potential to address the following issues:

- E-Health applications hold considerable potential to strengthen existing health systems, improve service delivery and address many of the pressing health problems and large burden of disease in developing countries;
- Local governments as well as international donors, universities and NGOs are continually implementing systems in support of individual health interventions. In the absence of a countrylevel architecture to guide implementations, these systems are largely uncoordinated and, at best, not contributing as much as they could to strengthening in-country systems and, at worst, creating unsustainable systems and interoperability issues.
- Galvanize the efforts of others to see country-level health information as an integrated whole such that routine information can be collected more accurately and efficiently and contribute to the country public health information system
- The implementation of an architectural methodology along with key implementations and evaluations in a reference developing country will act as a timely demonstration of the benefits of this approach that can be advocated more widely.
- Existing Enterprise Architecture Projects

HEALTH METRICS NETWORK

The Health Metrics Network (HMN) framework, version 2 is the first example of a high level design for HIS and provides much of the initial work on a systematic approach to HIS design and implementation. Version 3 of the HMN framework will elaborate many of the existing concepts and more fully develop the EA approach .

THE OASIS PROJECT

The Open Architectures Standards and Information Systems (OASIS I) project has established a program to develop an enterprise architecture approach at a country and implementation level and is harmonized with the HMN framework project. The OASIS project has been further elaborated in the OASIS II and Open Architectures projects funded by the IDRC and Rockefeller Foundation, respectively, which contain the following three foundational activities:

- Reference implementations in selected developing countries;
- Develop and document selected architecture artifacts (building blocks) appropriate for developing countries;
- Develop a Health Enterprise Architecture Framework (HEAF) for developing countries.

The OASIS and Open Architecture projects are being developed by a core group of organizations coordinated through Jembi Health Systems (a South African NGO specializing in eHealth implementations) and including the WHO Healthcare Informatics Department, the Regenstrief Institute, Pangaea Global AIDS Foundation and InSTEDD, supported by a global consortium of experts, collaborators and developers of similar projects.

REFERENCE IMPLEMENTATIONS

Reference implementations are the backbone of the OASIS and Open Architecture projects and involve the development of architectures, in response to identified in-country needs. This activity responds both to the existing need for greater design of in country HIS and the window of opportunity that exists to improve the design of systems before the level of infrastructurebecomestoowidespreadendentrenchedtochange. Existing implementations at a general level are already underway in Rwanda and Mozambique, with several other country-level implementations under consideration.

BUILDING BLOCK DEVELOPMENTS

EA frameworks will have little value without the means to implement. The building blocks activity seeks to document and, where necessary, foster the development of key architectural building blocks, such as software, policies etc. The activity draws much of its methodological framework from successful collaborative open source projects such as the Open-MRS collaborative and the DHIS/HISP program. However, building blocks are not necessarily or exclusively open source. The aim is to work with any viable and appropriate business model (open, proprietary etc) or project configuration (individual, collaborative, etc). The methodology and vision itself creates a strong bias in favor of building blocks that supportanopenarchitectureandopenstandardsbyexposingopen interfaces and promoting interoperability at an appropriate level allowing them to be integrated within multi-component systems.

HEALTH ENTERPRISE ARCHITECTURE FRAMEWORK (HEAF) DEVELOPMENT

The Health Enterprise Architecture Framework (HEAF) development activity seeks to take the lessons learned from the Reference Implementations and use this to inform the development and evolution of a general framework that can be re-used in other settings. When combined with the results of the Building Blocks development activity, the end result is a framework that can be customized on a country-bycountry basis to rapidly create a design blueprint to guide the selection, development and integration of new and existing components into appropriate HIS. The overall aim of the HEAF project is to develop and publish the specifications of a robust, scalable and interoperable open architectural framework to allow for the construction and deployment of integrated eHealth systems for the GS, with the initial focus in Africa. The main project deliverables include the first version of an open Health Enterprise Architecture Framework (HEAF) for African Countries, consisting of a general methodology for architectural framework development, customization and implementation that aims to specify the business and architectural requirements of an integrated eHealth System. Deliverables will also include a library of software artifacts that can be used to assemble health systems. Existing work, including the Open Group Architectural Framework (TOGAF) and the HMN architectural framework as well as the current successful deployments from other countries will be the starting point for this work; including reviews of current successful experiences of deploying large and complex integrated eHealth systems in developed and developing countries.

CURRENT PROGRESS

REFERENCE COUNTRY IMPLEMENTATIONS

Progress has been made elaborating EA projects in two African countries (Rwanda and Mozambique) and there are elements of projects in at least two other countries (South Africa and Zimbabwe). Some progress has also been made in plans for capacity development programs and the adoption or implementation of a web-based repository providing open access to the framework and serving as a repository for classified information and reviews of building blocks, standards etc.

RWANDA

Significant progress has been made on the Rwanda reference implementation. In November 2009, a technical consultation was hosted by the WHO Healthcare Informatics Department in Kigali, resulting in a high level set of architectural artifacts, including a high level functional domain analysis and interoperability profiles for several key information systems. During the next phase of the project a comprehensive functional requirements analysis will be carried out. Progress has also been made on integrating data from two key information systems (OpenMRS and TRAC), using an emerging standard for aggregated data integration (SDMX-HD).

MOZAMBIQUE

Significant progress has been made in developing local capacity for EA and HIS development in Mozambique. The MOASIS (Mozambique OASIS) group is attached to the Universidade Eduardo Mondlane and has an agreement with the Ministry of Health to assist with HIS development in Mozambique. An initial survey has provided details of many of the key HIS implemented in Mozambique. During the next phase, the full architectures will be elaborated into an

BUILDING BLOCKS

Progress on the definition and documentation of key building blocks includes architectural reviews of some software applications, including OpenMRS and Siga Saude as well as a review of applicable standards. Progress has also been made in the integration of applications such as OpenMRS, the District Health Information System (DHIS) and TRACnet.

HEAF DEVELOPMENT

Some progress has been made on harmonizing the tools and methodologies for framework development, including establishing a consortium of methodologists in South Africa at the University of KwaZulu-Natal, the Medical Research Council and the Meraka Institute. A proposal for an "eHealth Enterprise Architecture for Emerging and Developing Countries", including an environmental scan and elaboration of business requirements has been submitted to the International Standards Organization. Initial steps have been taken towards the development of a common requirements definition methodology and template.



MICHAEL BAINBRIDGE

PRINCIPAL CONSULTANT ASE LTD

Mike has been a leading figure in Clinical Informatics for 25 years working both for Government and Industry. He has designed and brought to market leading Clinical Computer Systems for the General Practitioner and Family Practitioner.

He participated in the 2003 negotiation of the IT elements of the current General Practitioner Contract in the UK; linking, for the first time, reimbursement to the quality of data (and therefore care) that is delivered.

He led the Clinical Architecture team at NHS Connecting for Health (NHS CFH) for 6 years and continues to deliver strategic input. This team has innovated hardware design as well as clinical interface design. This has resulted in the production of safe, standard interfaces for the both professional and citizen to use. Much of this work is now a UK National Standard and also freely available.

As a former General Medical Practitioner and medical informatics expert, Mike brings a unique insight to the field. In 2007, Mike was voted 'UK Health ICT champion'. He was recently appointed the UK representative on the IMIA General Assembly.

He is employed as the Chief Clinical Architect at ASE Consulting Ltd UK.


NGAI-TSEUNG CHEUNG

CHIEF MEDICAL INFORMATICS OFFICER HOSPITAL AUTHORITY HONG KONG

NT Cheung is the CMIO of the Hong Kong Hospital Authority and is also the Consultant for eHealth for the Hong Kong Government. He has over 20 years experience in health informatics, and has worked on areas as diverse as clinician friendly user interfaces, clinical coding and documentation, information and systems architecture, clinical data mining, support, physician order clinical decision entrv. risk management, clinician engagement, change management, and private-public interface. His current work focuses on takingtheHospitalAuthoritiesClinicalManagementSystem(CMS) on a generational leap to the next level of computerized record system functionality to improve the already world-class facilities in the CMS for the documentation and effective management of diseases and care, and on working with the government and other healthcare stakeholders to extend the benefits of eHealth for all the citizens and clinicians of Hong Kong.

As the head of health informatics in the Hospital Authority, NT Cheung has taken the Authority from a virtual "green fields" site in 1991 to today's situation where clinical information systems have become an indispensable part of the care delivery process for 30,000 clinical users. The Authority's Clinical Management System (CMS) is a comprehensive integrated clinical suite managing well over 7 million patient records, and includes what is probably the largest single longitudinal electronic patient record database in the world today.

NT is active in the informatics research and education communities, and is a frequent speaker at international conferences. He holds a medical degree from the University of Sydney and a Master's degree in computing science from Imperial College, London.



DAVID LUBINSKI

PROGRAM DIRECTOR PATH

David leads a team focused on developing and applying approaches to improve the design and development of health management information systems for low resource countries. Central to this work is the development of a systematic architected and rational approach to design and development. Lubinski brings more than 30 years of experience in commercial, government and non-governmental organizations focused on health information systems. Prior to his current assignment David was the chief technology officer of the Health Metrics Network a partnership of the World Health Organization. His experience includes nine years leading Microsoft's global healthcare strategy as well as senior assignments at Digital Equipment Corporation. Lubinski holds a certificate in enterprise architect from the Open Group Architecture Framework (www. opengroup.org) and has completed postgraduate international management training at INSEAD in Fontainebleau, France.



DAVID ROSS

EXECUTIVE DIRECTOR PUBLIC HEALTH INFORMATICS INSTITUTE

Dr. David Ross directs the Public Health Informatics Institute, a program of the Task Force for Global Health, which is affiliated with Emory University. The Institute supports public health practitioners in improving their use of information and information systems to achieve greater impact on individual and community health. He received his Doctor of Science degree in applied math and operations research from The Johns Hopkins University. His career spanshealth care services research and administration, environmental health research, and public health and medical informatics consulting. He served in scientific and senior management roles at the U.S. Centers for Disease Control and Prevention (CDC), retiring as a commissioned officer of the U.S. Public Health Service in 1998. He also worked as an executive with a leading health information technology firm implementing clinical information systems. He served on the Institute of Medicine's (IOM) core committee for the evaluation of the U.S. government's global HIV/AIDS PEPFAR program, the IOM panel recommending the research agenda for public health preparedness, the IOM Committee on Public Health Strategies to Improve Health, is a commissioner on the Certification Commission for Health Information Technology (CCHIT) and advises the World Health Organization's Health Metrics Network Technical Working Group.

CHRISTOPHER SEEBREGTS



SENIOR MANAGER MEDICAL RESEARCH COUNCIL SOUTH AFRICA

Dr Chris Seebregts is a Senior Manager, Biomedical Informatics in the e-Health Research and Innovation Platform at the South African Medical Research Council, an honorary associate professor in computer science at the University of KwaZulu-Natal, a Lead Health Technology Consultant for Pangaea Global AIDS Foundation and founder of Jembi, a South African NGO implementing open eHealth and information systems in Africa. He has postgraduate degrees in medical biochemistry, computer science and software engineering and has worked both in the public and private sectors in biomedical and informatics research, information technology management and software development. He is part of the leadership of the OpenMRS consortium and principal investigator of the Open Architectures, Standards and Information Systems for healthcare in developing countries project and Free State Intervention on HIV Resistance and Sustaining Treatment projects. His main areas of interest are the design and development of health information systems, open enterprise eHealth architecture, biomedical informatics, and HIV/AIDS treatment failure.

PARALLEL SESSION 3.5:

MANAGING COMPLEX DATA IN HEALTH CRISES:

CHALLENGES FOR NATIONAL HEALTH INFORMATION SYSTEMS



SPATIALLY ENABLED DECISION SUPPORT SYSTEMS: ENABLING BETTER HUMANITARIAN COORDINATION

KEITH DOYLE

IMMAP

In any given emergency health is only one of many clusters. Information systems for each cluster are often created on the ground and the wheel is invented time and time again. To compound this issue such systems are never compatible and hence we miss out on inter-rational analysis between each cluster.

GIS can help bridge this gap between such information systems. Commonly people identify GIS as a tool for designing maps. Although this is true, GIS can accomplish a lot more. Consider all clusters being able to represent their vulnerability assessments and assistance on maps. GIS can link all information for each cluster by a simple, common parameter: location. Once such information can be displayed together it opens up a whole new world to analysts.

However, classic GIS is not sufficient for this cause. If a system is to be embraced by all it needs to make peoples work easier. The following requirements for such a system are necessary:

- It must be easy to use. Non GIS people should be able to utilise the system
- Sharing of information should be seamless
- Changes to the system should be easily committed
- Live analysis on the data should be possible

My presentation to this forum will discuss this in more detail and using iMMAP's OASIS as a showcase for a tool which can facilitate this type of information sharing, analysis, and flexibility.

EARLY WARNING AND RESPONSE SYSTEM, EWARS, A CRITICAL COMPONENT OF HEALTH INFORMATION SYSTEM IN COMPLEX EMERGENCIES SITUATION.

AUGUSTO PINTO

MD, MEDICAL EPIDEMIOLOGIST, WHO SEARO, DSE SUBUNIT, BANGKOK, THAILAND.

INTRODUCTION

Whenever and wherever a crisis strike, for whatever cause, natural as cyclones or tsunami, biological as epidemics or pandemics, human causes as war or civil strife, there is an urgent need to understand what happened, in which dimension and how many people are affected.

At the same time is extremely urgent to set up information systems, able to monitor since the beginning the severity and the possible development of the situation to prevent further catastrophic events that can ravage the already affected population.

Complex emergencies are defined as "situations of war or civil strife affecting large civilian populations with food shortages, and population displacement, resulting in excess mortality and morbidity" ¹

Infectious diseases can play a major role in complex emergency conditions, especially when there is a massive disruption of the health system, degradation of the water supply and sanitation system and reduced access to basic heath care. For that reason the setting up of an EWARS system is one of the most urgent actions to be implemented soon after the occurrence of a disaster.

CONTEXT SPECIFICITY

Each crisis has its own specificity, due to the origin, the affected population, the preexisting situation, the social economic development and the preparedness capacity of the affected country.

Thus, according to that, there are several specific conditions that have to be taken into consideration when implementing a EWARS in complex emergency:

- Identification of the affected population
- National counter part and political situation
- Partners
- Security situation
- Existing infrastructures

IDENTIFICATION OF THE AFFECTED POPULATION

Understanding how big is the population affected and measure that, is one of the most complex a difficult problems to be solved in the first hours/days of the crisis. Different methods can be used, from real time satellite images to the use of methods for estimating the dimension of the problem.²

However out of the quantification aspect, there is the immediate need to understand who is affected, which part of the population is at major risk, namely, children, women, elderly, young population, etc. This information is critical at the beginning of any humanitarian action, to drive the immediate response and avoid delay that in some cases can be fatal.

The sources for this information can be various, namely, local authorities, NGOs, international agencies, local leaders, affected population, etc.

NATIONAL COUNTER PART AND POLITICAL SITUATION

Setting up an Early Warning System in a complex emergency condition is a complex operation which implies inevitably the close collaboration of the national counter part. The involvement of the local government can imply the adaptation of the existing surveillance system to the new crisis condition, or the implementation of a new system which anyway need to fit with the pre-existing network.

Most of the time, local government are very kin to collaborate with humanitarian support and the health personnel is always available to participate to the implementation of new system. However in some specific conditions, determined by the existing political crisis, especially during civil wars, or in countries with closed military dictatorships, sharing information about epidemic can become a sensitive issue, that need a very strong diplomatic action to allow the accomplishment of the pre defined objectives.

The working environment some time can be very difficult, especially due to different demands and needs of different

partners and national counter part. International community is asking for clear and net transparency of information to prevent morbidity and mortality and national counter parts are sometimes much more worried abut internal security and control of information.

Local security becomes more and more a concern. Humanitarian intervention are becoming more and more frequently target of deliberate attacks aimed to discourage the presence of witness of the occurring violence among the affected population especially during war or civil wars..

An information system has its own roots at community level, among the most affected and the most in need to collect and report as soon as possible the most sensitive data about outbreak occurrence able to trigger immediate public health actions.

For that security need to be considered carefully in setting up and implementing an EWAR system for communicable diseases.³

OBJECTIVES

The main goal of an Early Warning System for infectious diseases is to reduce Morbidity and Mortality due to epidemics.

Specific objectives can be identified as follow:

- Allow immediate detection and reporting of outbreaks
- Trigger immediate response to control outbreaks
- Provide health indicators to help stake holders and partners for monitoring public health intervention
- Monitor trends of specific diseases under surveillance
- To assess health structure workload in order to optimize resource allocation

KEY ATTRIBUTES

The setting up and implementation of an Early Warning System in complex emergencies imply the application of several critical attributes to make the operation efficient and effective.

The immediate response to a humanitarian crisis, of any kind of nature, imply the coordination of various partners, from UN agencies, to NGOs, to local and national counter part and military organization from the affected country as well as from neighborhood countries or international peace keeping army.

In situation like these ones acceptability is the first attribute to be guaranteed to ensure the setting up and implementation of the EWAR system. The system cannot run without the close collaboration of all partners, especially because each partner is operating in a different area and each partner can have different responsibility. Thus acceptability is the glue which keeps all the different pieces of the mosaic together.⁴

Simplicity and feasibility have to be taken strongly in consideration to allow the setting up of a system which can comply with the difficult and complex situation of a crisis and at the same time to ensure the accomplishment of planned objectives. The design of the system needs to be drawn according to the peculiar situation in which the crises happen.

Usually data collection has to be very limited and fully finalized to specific useful and action oriented indicators. Cases and deaths can be collected on daily as well weekly basis as aggregate data. Rumors detection is critical and a network of daily communication can be settled among partners and communities to early detect possible outbreaks.

Information have to be limited to epidemic prone diseases prioritized according to the specific kind of crisis and the risk assessment conducted in the early hours of the occurrence of the disaster.

In complex emergency the sensitivity of the system play a major role. The immediate detection of outbreak is critical, given underlying conditions as the high density of population, the increased risk of mortality due to concomitant conditions as, lack and poor quality of water, limited food availability, scarce hygiene and sanitation conditions and high density of the displaced population. In this condition a case of measles become a very threatening and alert condition as well a case of cholera or a case of hemorrhagic fever. It is evident thus that the system should be sensitive enough to produce a signal or an alert as soon as possible in the way to trigger an immediate investigation able to verify the existence of a threatening condition.

Specificity will depend very much from the support functions of the system, namely the laboratory support, the training capacity for the front line personnel and the use of computer application able to analyze data automatically and produce signals according to pre defined indicators or thresholds.

Laboratory support unfortunately remains always an area difficult to implement in crisis. It depends very much from the existing local conditions and capacities. More developed the country easier the support, less developed the country more difficult is to activate immediately a laboratory which could guarantee diagnosis of good quality.

Performance of the system needs to be monitored constantly to guarantee the representativeness, efficiency and effectiveness of the system. Timeliness and Completeness are indicators as well attributes that become the thermometer of the system. Without constant monitoring activities of these two indicators there is a high risk to have misleading information which will lead to erroneous decisions in a situation where information is critical to lead focused public health intervention.

MORTALITY DATA

Mortality data are of paramount importance to monitor the severity of an epidemic as well as to monitor the magnitude of the crisis and the impact of the humanitarian interventions.

Unfortunately, the collection of mortality data is quite difficult in crisis condition and needs specific systems to be set up according to the dimension and the kind of disaster.

Crude mortality rate (CMR) and under five mortality rate (U5MR) are key indicators to define an emergency. Based on Sub Saharan crude mortality rate in normal condition (0.3-0.6 deaths per 10,000 per day) a threshold has been constructed around s1 per 10,000 deaths per day as a useful thresholds for formally declaring an emergency. For under five children the threshold is defined at 2 per 10,000 per day, because the U5MR is usually the double of the CMR.(5)

However even though these indicators are recognized as the most sensitive to monitor a crisis, their collection poses several problems.

Usually in a crisis people are settled in different possible shelters, and more an more, now a days, the image of one camp hosting all refugees of a crisis is less and less happening.

Refugees or displaced population are usually dispersed in large areas, and some time they are in organized camps, others they improvise spontaneous camps, in other they search hosting facilities in neighborhood houses or villages, in others they move forward as far as possible from the affected areas searching refuge in the bush, in other conditions they can be hosted in churches, school or abandoned factories.

These possible conditions determine the difficulty to collect reliable and continuous figures of mortality in prospective way. Health facilities are not a good place to collect deaths information because usually in complex emergency people die in the shelters, or elsewhere and the family usually don't bring the body to the health facilities before to bury in an improvised cemetery.

Thus daily counting graves in these areas can be a possible source of reliable mortality data. Another possible way is to have community health worker who can daily visit shelters and check if any death has occurred.

In situation when the affected population is very large it is quite difficult to carry out these operations, able to monitor mortality data. In these conditions retrospective mortality surveys can give a good estimation of the severity of the crisis. However the implementation of these surveys needs strong technical and logistic support as well as clear understanding among partners, especially with the national counter part, to ensure the quality of the data and ensure the endorsement of the results.

DATA FOR ACTION, RESPONSE

As said before, simplicity and feasibility are two critical attributes of the system to ensure that the system can work and can give in time the required information to trigger an immediate action.

Base on these very simple principles a EWAR system needs therefore to collect very few information, very critical and useful to allow the humanitarian intervention to be focused on the most critical and urgent needs.

Usually a EWAR system for communicable diseases collect number of cases for a limited number of epidemic prone diseases defined by the risk assessment of the specific situation as well as from the epidemiological profile where the crisis strike. Aggregated numbers of cases are collected daily or weekly and usually by two main age groups, under five years and over five years of age.

This information is good enough to produce indicators able to generate signals for an eventual outbreak, through pre defined thresholds. Usually thresholds can be defined in terms of absolute numbers (e.g. 1 case of measles, 1 case of hemorrhagic fever, etc) or based on relative value as the increase of 1.5 folds the average of the previous 3 weeks or on probability tests using Poisson test or on statistical cut off points, as Standard deviation or percentiles.

Data produced needs to be immediately available and easily interpreted to allow stakeholders to trigger actions. Usually EWAR system are put in place with computer applications that can generate immediately signal of alerts, rate and proportions in tables, graphic and maps to help as much as possible operators in difficult conditions.

However EWAR system for epidemic prone diseases is just a component of elements contributing to control epidemics. In order to increase the effectiveness of the response, it is necessary to cross check the EWAR information with other system able to collect information about: Population, Mortality, Vaccination coverage, water and sanitation, nutritional status, food distribution, shelter conditions and drug supplies.

SUSTAINABILITY

As all intervention in emergency situation there is a need since the beginning to assess the sustainability of the intervention especially in the long run. In many conditions, doesn't matter if in natural disasters or in disasters generated by conflict, crisis can last for very long time, as the situation in Darfur in Sudan, Somalia, Kivu in Democratic republic of Congo, Afghanistan, refugee camps between Myanmar and Thailand and many other examples.

For that reason humanitarian intervention in collaboration with national counter part needs to forecast enough resources to maintain the leaving condition of the affected population to an acceptable level able to guarantee good nutrition, safe water supply, good shelters and good health assistance to the affected population. In some conditions, the experience acquired in setting up a EWAR system in complex emergency condition has been good enough to convince the local MOH to adopt and expand soon after the crisis the same principles, objectives and methods to the national surveillance system.⁶

However what is also true in terms of possible sustainability is the capacity of the pre existing surveillance system for Communicable Diseases. Countries with updated surveillance system with a strong EWAR component can easily adapt their system and sustain easily the information flow when a crisis of any kind of nature will strike.

CONCLUSION

This short overview based essentially on ten years of experience in different complex emergency situation allow us to identify some critical point to be taken always in consideration in setting up EWAR systems in crisis condition, namely:

- Close coordination among humanitarian agencies and national counter part
- Ensure simplicity and feasibility of the system to facilitate the achievement of the defined objectives
- Use of new technologies to enhance data analysis and immediate interpretation as well as communication also in the most difficult conditions
- Support the front line staff with efficient laboratory and training
- Integrate data produced by EWAR with other critical information from other information system
- Support strong response capacities to use data generated rationally to enhance the effectiveness of the system
- Use most appropriate method and techniques to collect data according to specific situations, especially for mortality data.

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Keith Doyle (MSc, BEng) has working been working in the humanitarian sector for the past eight years as a technical expert on information systems. His work in this period for INGOs and the United Nations has extended across Africa, Asia, and the Middle East. Currently Keith works as a Senior Information Officer for iMMAP.

IMMAP is a not-for-profit organisation whose mandate is the alleviation of pain and suffering of those in need. iMMAP accomplishes this important mission by providing decision makers at all levels with reliable, relevant, and timely information upon which to act.

Keith believes that it is the obligation of all humanitarian actors to facilitate optimal sharing of information among all actors in order to provide the best tools to decision makers in all contexts. His work with iMMAP has helped bridge the technological lag the humanitarian sector suffers with respect to the commercial sector. Through the development of tools to enable better information sharing and coordination he believes that we can be more effective in what we do.



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Since 1989 I moved again to work abroad in countries as Brazil, Albania, Europe, Africa, Thailand and South East Asia and have the chance to visit many others countries for short missions and emergency conditions.

In 2001 I joined WHO/CSR in Head Quarter office in Geneva as WHO medical epidemiologist to strengthen communicable diseases surveillance, Early warning system and response at country level in normal and crisis situations and in 2006 I moved to Bangkok to join the South East Regional Office in Bangkok always in the domain of Surveillance and Response of communicable diseases.

Health information system has always been one of main area of interest and actions, however since last 10 years I focus much more on surveillance, early warning and response to epidemics.

I had the chance to setting up and implement EWARS system in many countries during complex emergency situations, namely in Albania, Darfur Sudan, Chad, Sri Lanka, and Myanmar.



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Dr. Michael St. Louis serves as Associate Director for Science for the Coordinating Office for Global Health (COGH) at the U.S. Centers for Disease Control and Prevention (CDC). Dr. St. Louis has an extensive background in both science and program for HIV/AIDS, STDs, and other communicable diseases and public health problems. In recent years, he served as the founding Director of CDC's Global AIDS Program, founded and directed its large and successful program in Zimbabwe, and assisted in establishing the program office for the President's Emergency Plan for AIDS Relief (PEPFAR) in Washington. He has served in multiple leadership roles for emerging health situations across the U.S. Government, including in the response to Hurricane Katrina in New Orleans, and in leading coordination in planning and implementation of the global components of U.S. National Plan for Pandemic Influenza across CDC, NIH, FDA, and other components of DHHS. Through all of these, Dr. St. Louis has been deeply involved with surveillance and related health information systems for public health, and since 2006 he has served on the Technical Advisory Group of the Health Metrics Network (HMN). Since 2007, he has served as founding Chair of CDC's Surveillance Science Advisory Group.

Dr. St. Louis attended Harvard College and Harvard Medical School, studied economics at McGill, trained in pediatrics at Massachusetts General Hospital, and epidemiology in CDC's Epidemic Intelligence Services (EIS). He has published more that 100 articles in peer-reviewed journals on a highly diverse range of infectious disease, reproductive health, and other public health issues.

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