

Data Collection, Management and Surveillance: Using Smart Phones in Smart Ways

ISDS Webinar

November 10, 2011

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Who is participating?

As of Tuesday, November 8, 2011

- 166 people registered for this webinar
- Experience in mHealth among participants?
 - 24 mentioned no experience
 - 33 people mentioned experience working with technology
 - Developers: HealthMap, Sana MIT project, Allergy Alert apps
 - Implementers: South Africa, patient information in US clinics, Hajj, HIV testing practices, EMRs, researching daily mood
 - 109 didn't respond
- We are interested from learning from everyone on this webinar!

Presentation Outline

- HMIS: Current Practices and Challenges
- What is mHealth and eHealth?
- Tools and resources
- Practical applications of m/eHealth
 - Programs
 - Research
 - Surveillance
- Benefits and considerations of mHealth solutions

Who are we?

- Boston University School of Public Health Electronic Data Capture Team
- Our Goal:
 - Support integrating technology into research, teaching and programs in the Center for Global Health and Development at BUSPH
- Ongoing projects integrating technology:
 - Guest lectures on mHealth in MPH classes
 - Housing study in Worcester, MA
 - HIV Adherence Study in China
 - Study of the supervision structure of Health Extension Workers in Ethiopia
 - Omphalitis study in Zambia

Data from the Patient to the National Level

- Health Management Information System (HMIS)
 - An information system specifically designed to assist in the **management and planning** of health programs as opposed to the delivery of care
- Levels of an HMIS system
 - Patient management systems
 - Site based management information system
 - District, regional, national and aggregation and reporting

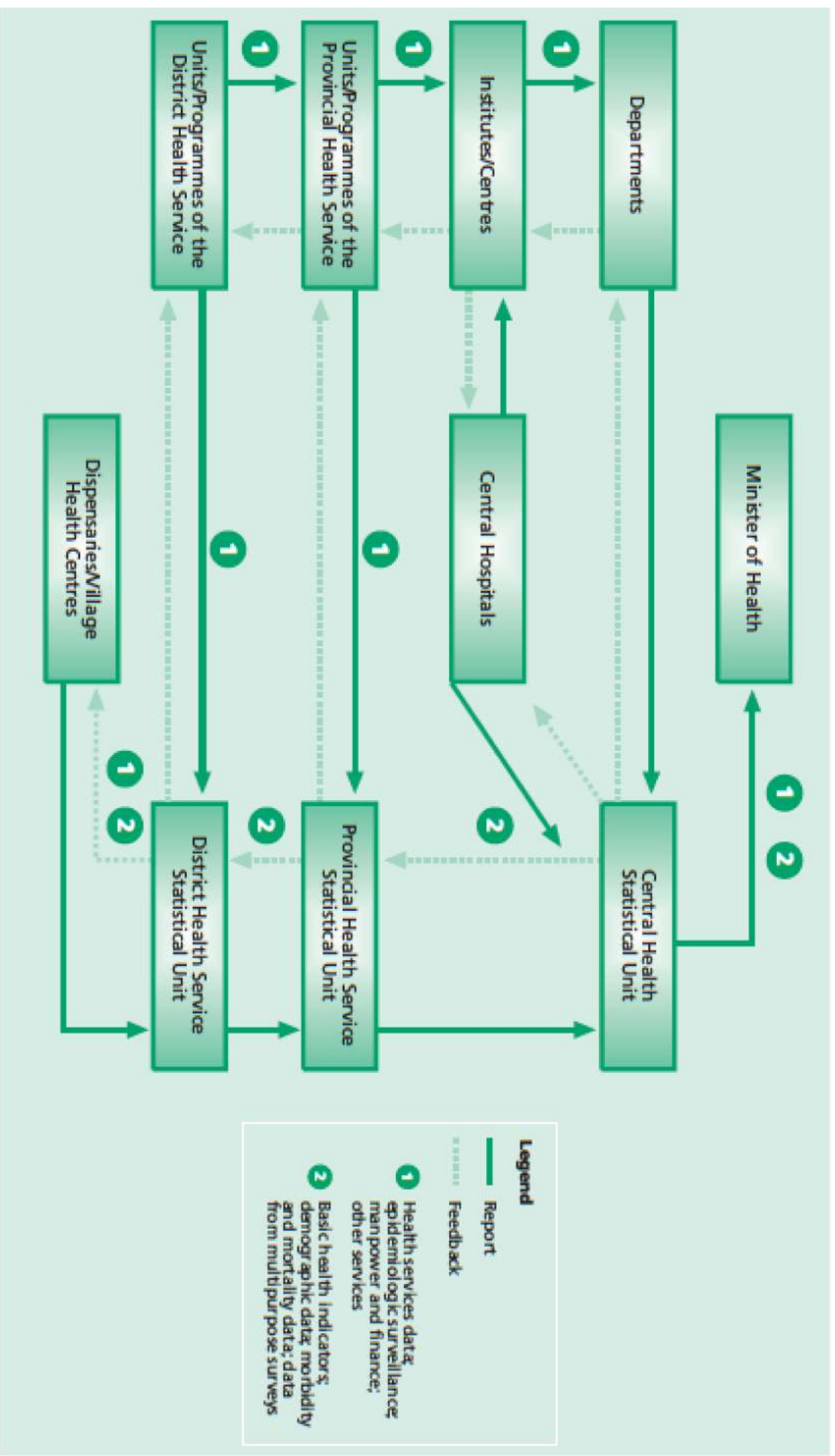


Photo: Courtesy of Mary Kratz



Photo: Courtesy of Nathan Golan; ICAP – Columbia University

Typical HMIS Data Flow



Challenges of Country Level HMIS Systems

- Challenges
 - Difficult to coordinate if multiple partners are involved in data collection and reporting
 - Healthcare provider experience/time with data
 - All levels usually don't receive timely feedback
 - Loss of data, poor data quality, under/overreporting
- Consequences
 - Reliability and validity of the data is undermined
 - Limited use of the data at all levels of the system
 - Yield on investment of collecting data is diminished
 - 'Garbage Bias'

'Garbage Bias' made simple:

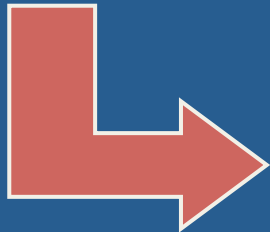
Garbage (lousy data)



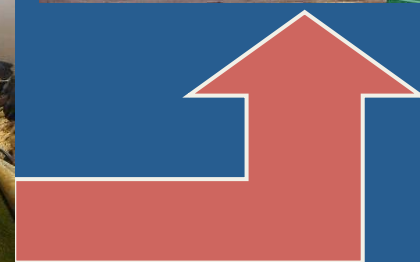
Garbage processing
(data cleaning)



Compact processed
garbage – prettier
but still garbage
(results)



Garbage collection
(data harvesting)



From the National to the International Level

- Challenges
 - Multiple stakeholders: PEPFAR, Global Fund, UNAIDS, World Bank, UNICEF, WHO, etc....
 - Differences in indicators, denominators and time of reporting
- Consequences
 - Estimates due to quality/availability of data
 - Inability to have timely, accurate data to inform policies and action

Opportunities

How can technology improve current systems?

What is eHealth and mHealth?

- **eHealth:** Use of any type of technology to support health services and information gathering and dissemination¹
- **mHealth:** Use of mobile devices to support real time data collection, training, programmatic interventions for health services²

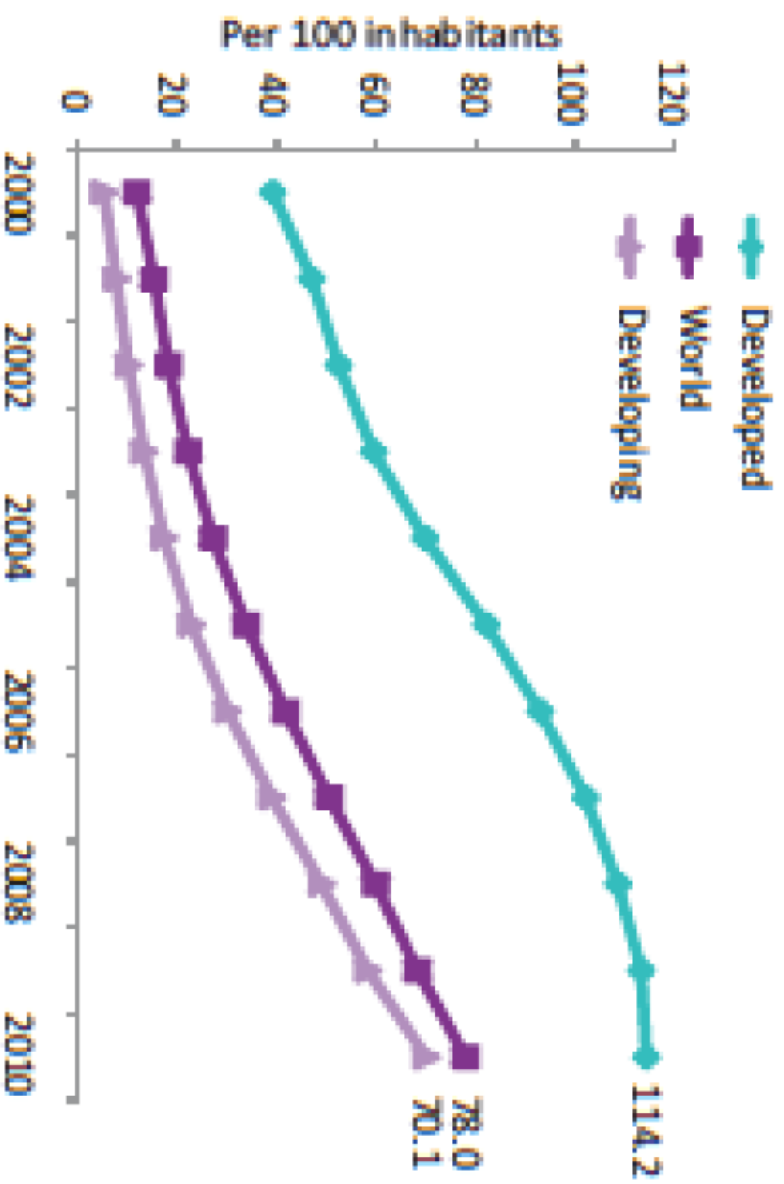
¹ Vital Wave Consulting: mHealth for Development, 2009; ²Germanakos, 2005

Opportunity Knocking...

- 5 billion people have cell phones
 - 70% in low and middle income countries
- 83% of countries use at least one e/mHealth service
 - 59% health call centers
 - 54% managing emergencies and disasters
 - 49% mobile telemedicine
- Greatest Barriers: competing health system priorities; evaluation of cost-effectiveness and availability of policies



People Love Cell Phones....no plateau yet



Source: ITU World Telecommunication/ICT Indicators database.

Gartner Says Android to Command Nearly Half of Worldwide Smartphone Operating System Market by Year-End 2012

Egham, UK, April 7, 2011 — Worldwide smartphone sales will reach 468 million units in 2011, a 57.7 percent increase from 2010, according to Gartner Inc. By the end of 2011, Android will move to become the most popular operating system (OS) worldwide and will build on its strength to account for 49 percent of the smartphone market by 2012

Android Phones predicted to take 49% of the smartphone market by 2012



Source: <http://www.gartner.com/it/page.jsp?id=1622614> Accessed: November 4,

Now what do we do with all these
'smart' and 'dumb' phones?

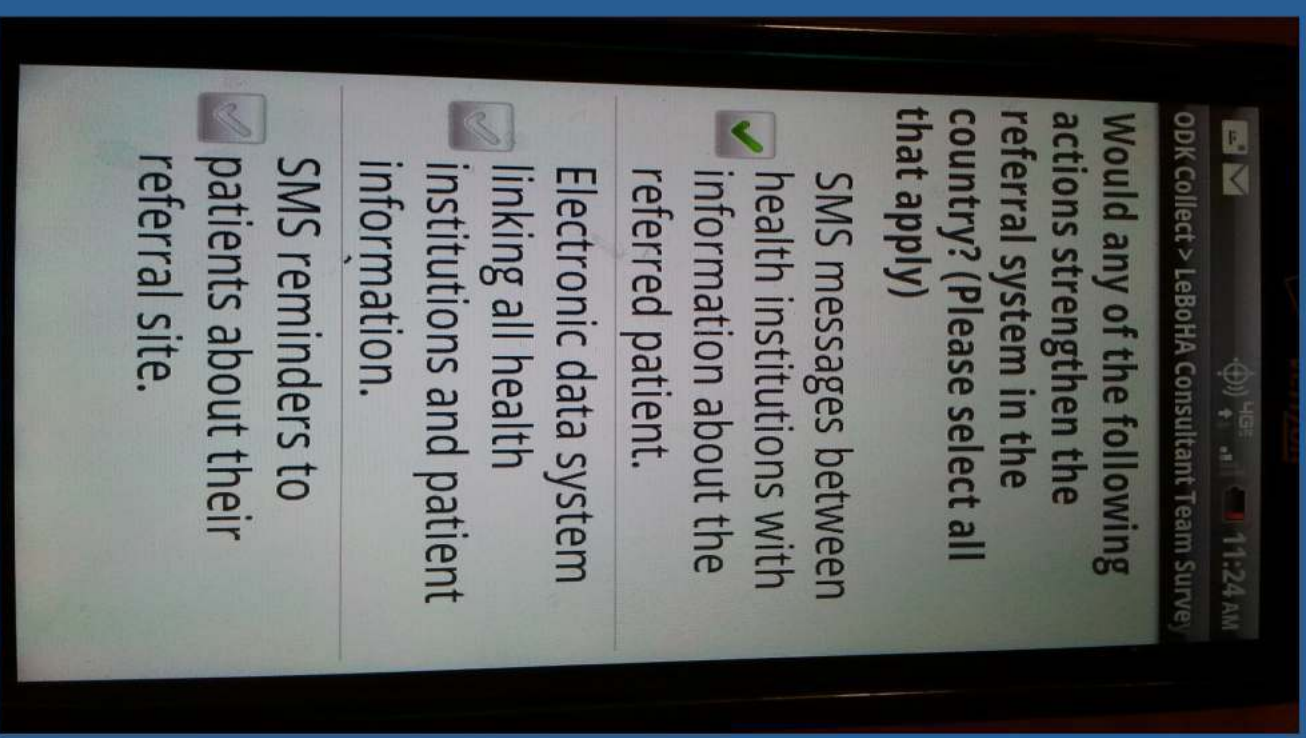
We need tools!



Open Data Kit (ODK)

Developed by University of Washington in 2008; open-source tools run on the Android platform

- **Build:** Build data collection forms
- **Collect:** Phone application to collect data
- **Aggregate:** System to aggregate collected data
- **Validate:** Ensure that Xforms built outside of ODK suite will work in ODK.
- **Briefcase:** Move data between different data sets
- **Voice:** Conduct remote questionnaire on any phone; responses collected via sound and keypad.
- **Clinic:** Smartphone-based medical record system.
- **Tasks:** Create tasks and push them out to phones.
- **Visualize:** Server-based tool to visualize data collected from ODK.



Source: <http://opendatakit.org/>¹⁷

eMOCHA

- Developed by the Johns Hopkins Center for Clinical Global Health Education
- Runs on Android platform
- System managed by a server, authenticates phones and can push and pull data from server to phones in real time

www.emocha.org

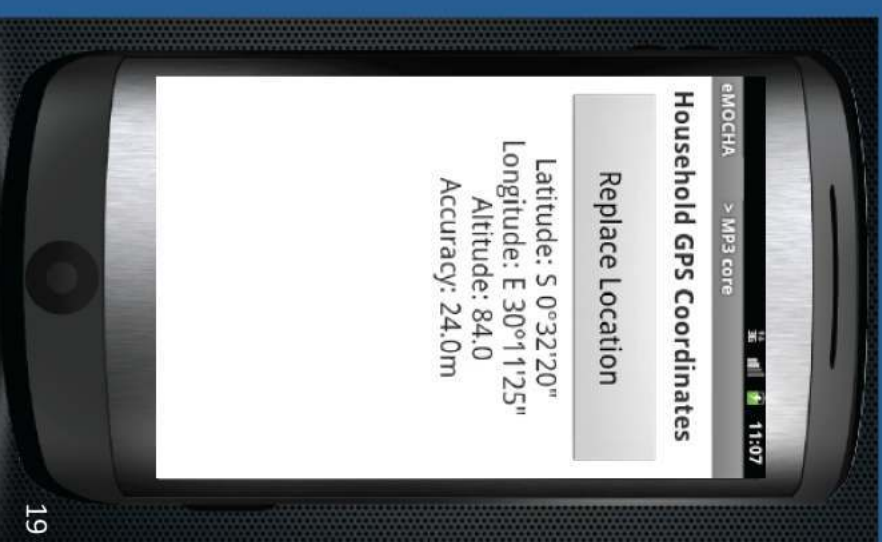
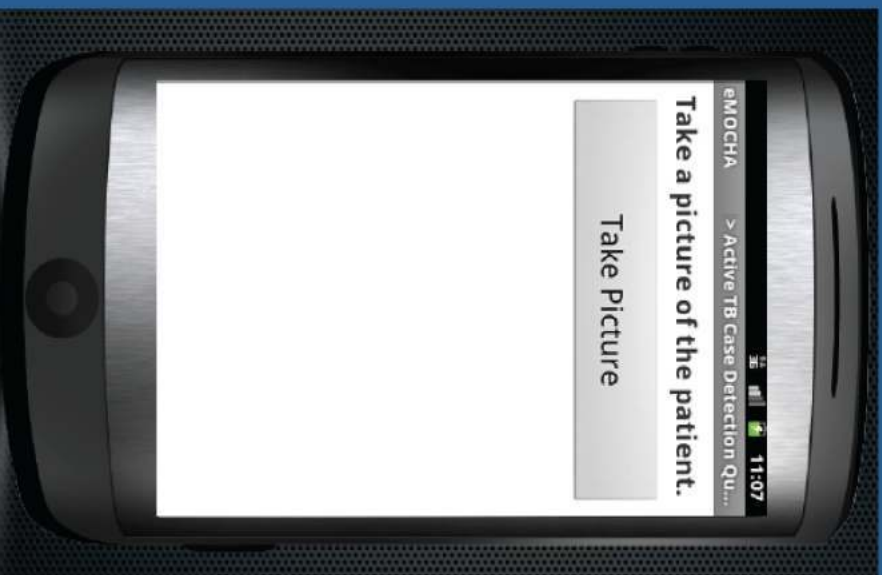


emocha
electronic mobile open-source
comprehensive health application



Collecting Data with eMOCHA

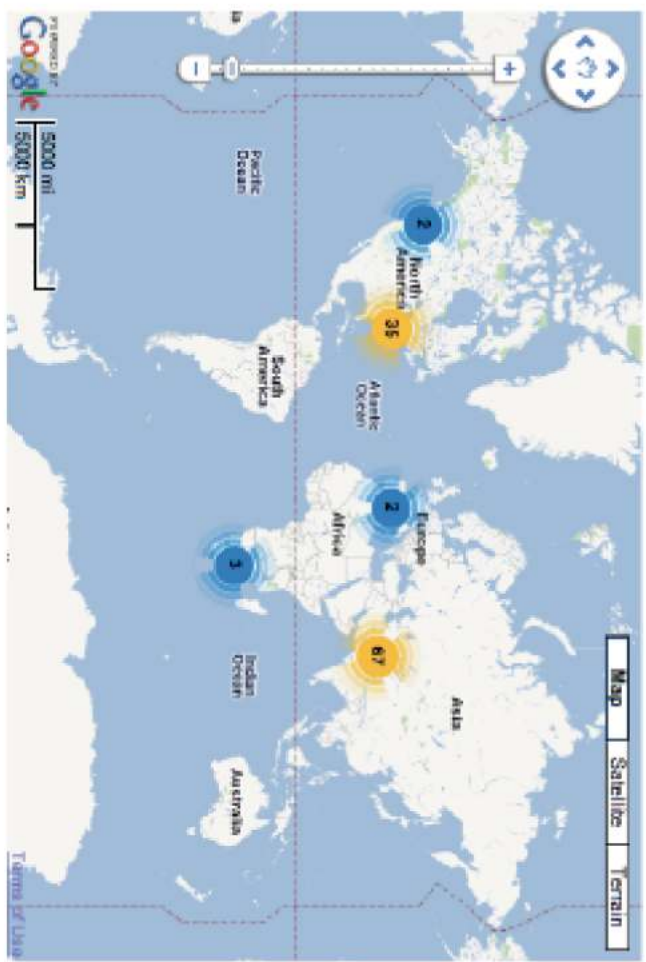
Generate Forms; Push forms to Phones with Question Types:
Single select, Select all, GPS tag, Photo capture, Voice record



Continuing Education with eMOCHA

Learning resources and trainings can be pushed to phones for ongoing learning with pre/post questionnaires built in to measure improvement in learning





View
Households Patients

FILTER
Number of patients in household
equals

Search

Other Phone-Based Data Collection Tools

- DataDyne (www.datadyne.org)
 - Social business; SMS Messaging Tools
- EpiSurveyor (www.episurveyor.org)
 - Design forms, collect data, SMS systems, backend data aggregation
 - Runs on Android, Blackberry and non-smart phones
 - Free, but increased pricing with tech support

Open Source Tools

Data Collection Systems: compatible with smart and regular phones

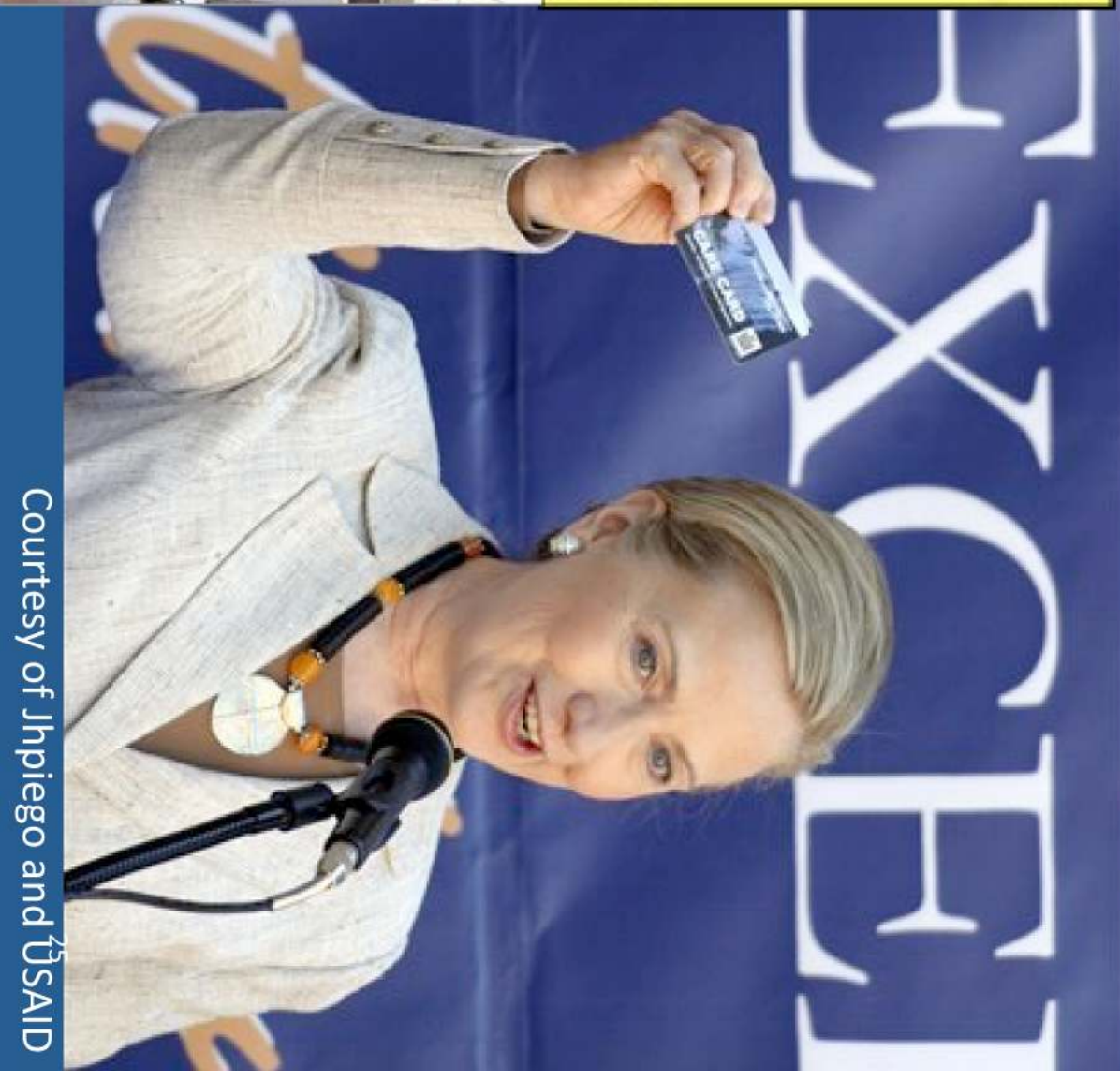
- Sana: MIT Project (www.sanamobile.org)
- EpiCollect (www.epicollect.net)
- Frontline SMS (www.frontlinesms.com)
- Rapid SMS (www.rapidsms.org)

Top 10 data collection tools:
<http://mobileactive.org/>

Examples of technology solutions in low-resource settings

- Electronic Medical Records
- Program Management and Implementation
- Research
- Surveillance

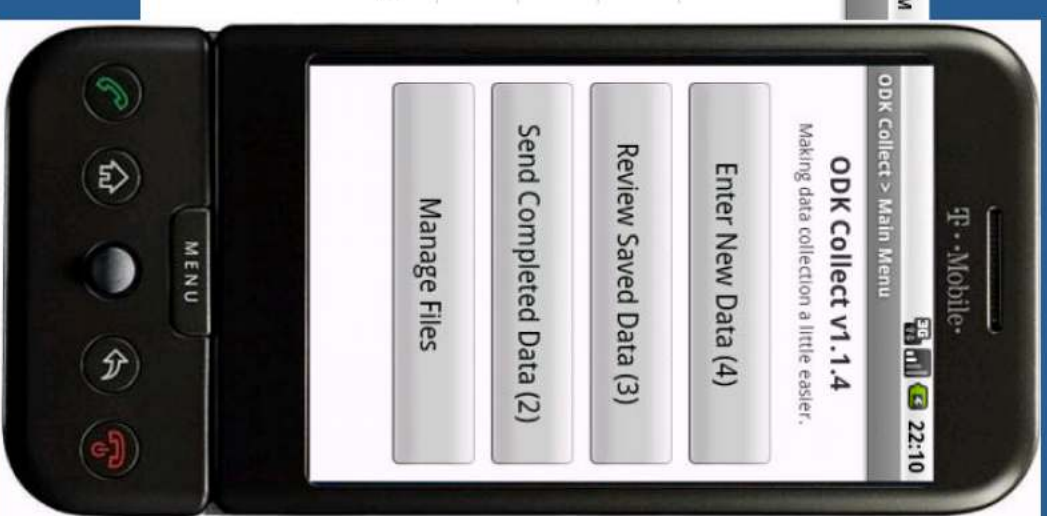
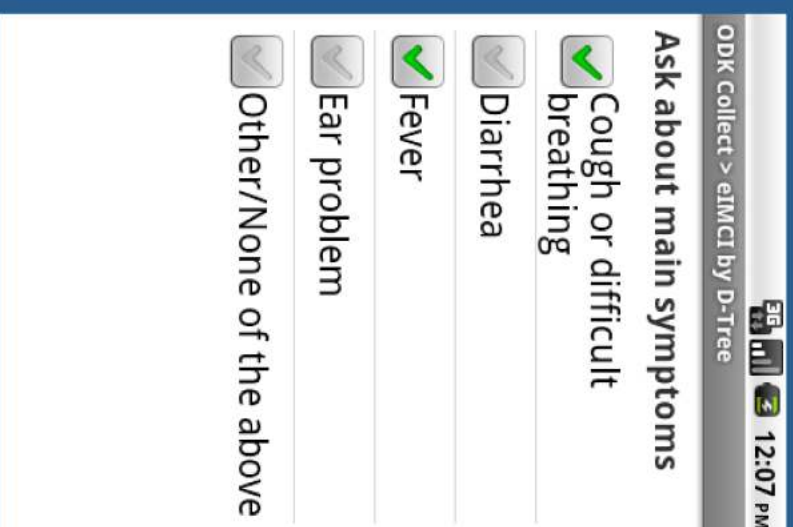
EMR and the Smart Card in Zambia



Courtesy of Jhpiego and USAID

Patient Reminders and patient level data collection

- Mobile device data entry and submission
- Use of SMS messaging for patients or providers



GPS mapping and Clinician Training

- GPS mapping of disease burden or service coverage
- Clinical decision support
 - Computer and held devices with specialized clinical decision-making algorithms

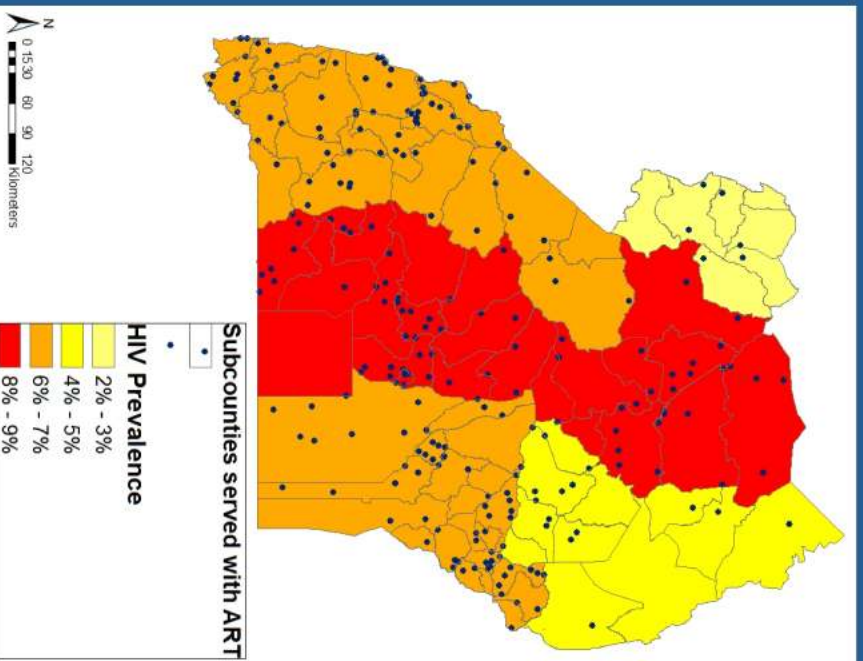


Photo Courtesy of
TheraSim, Inc.

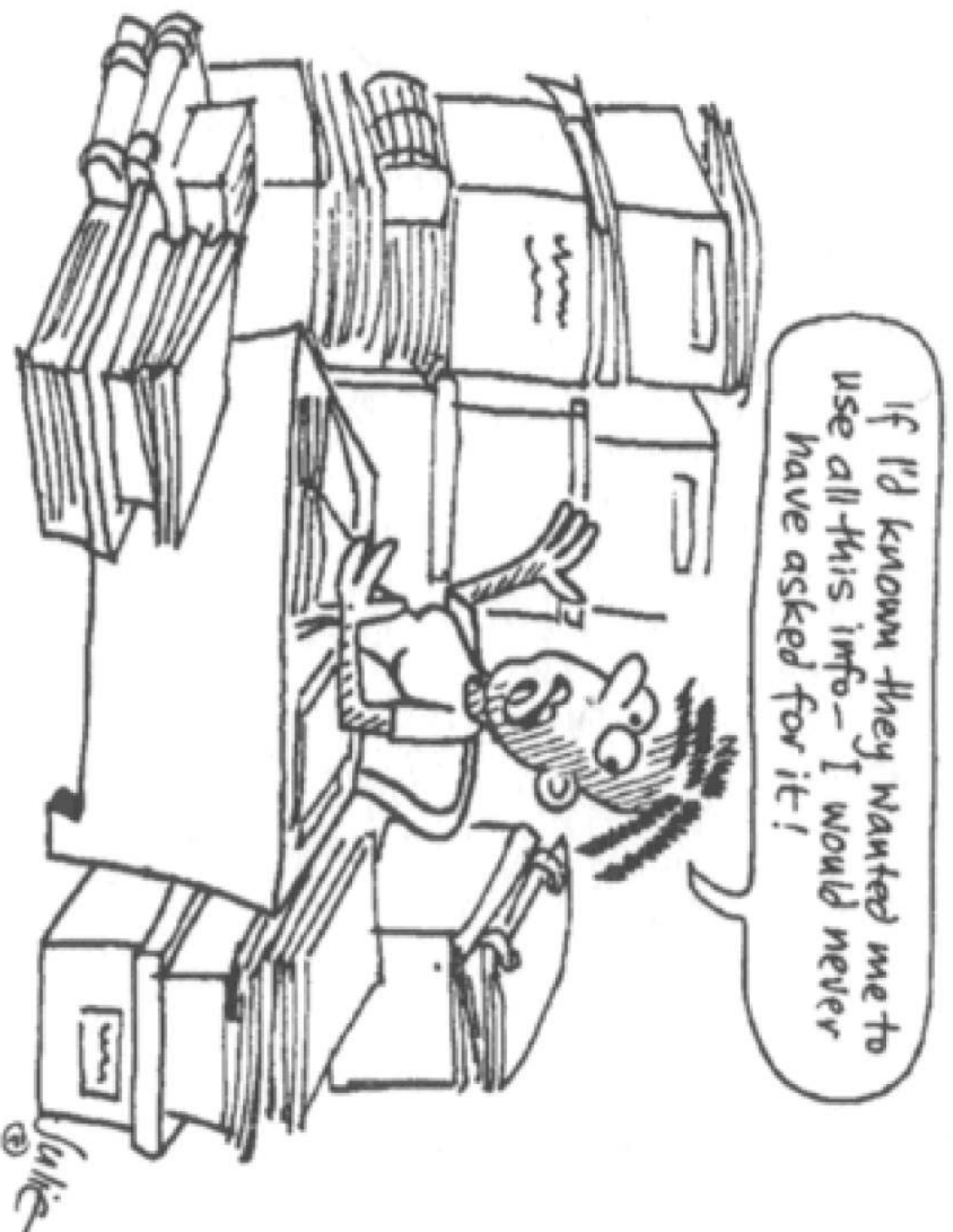


HIV Telemedicine in Ethiopia



Courtesy of Johns Hopkins University TSEHAJ Project

Research – So much paper, so little time...



Research... You've been lapped!

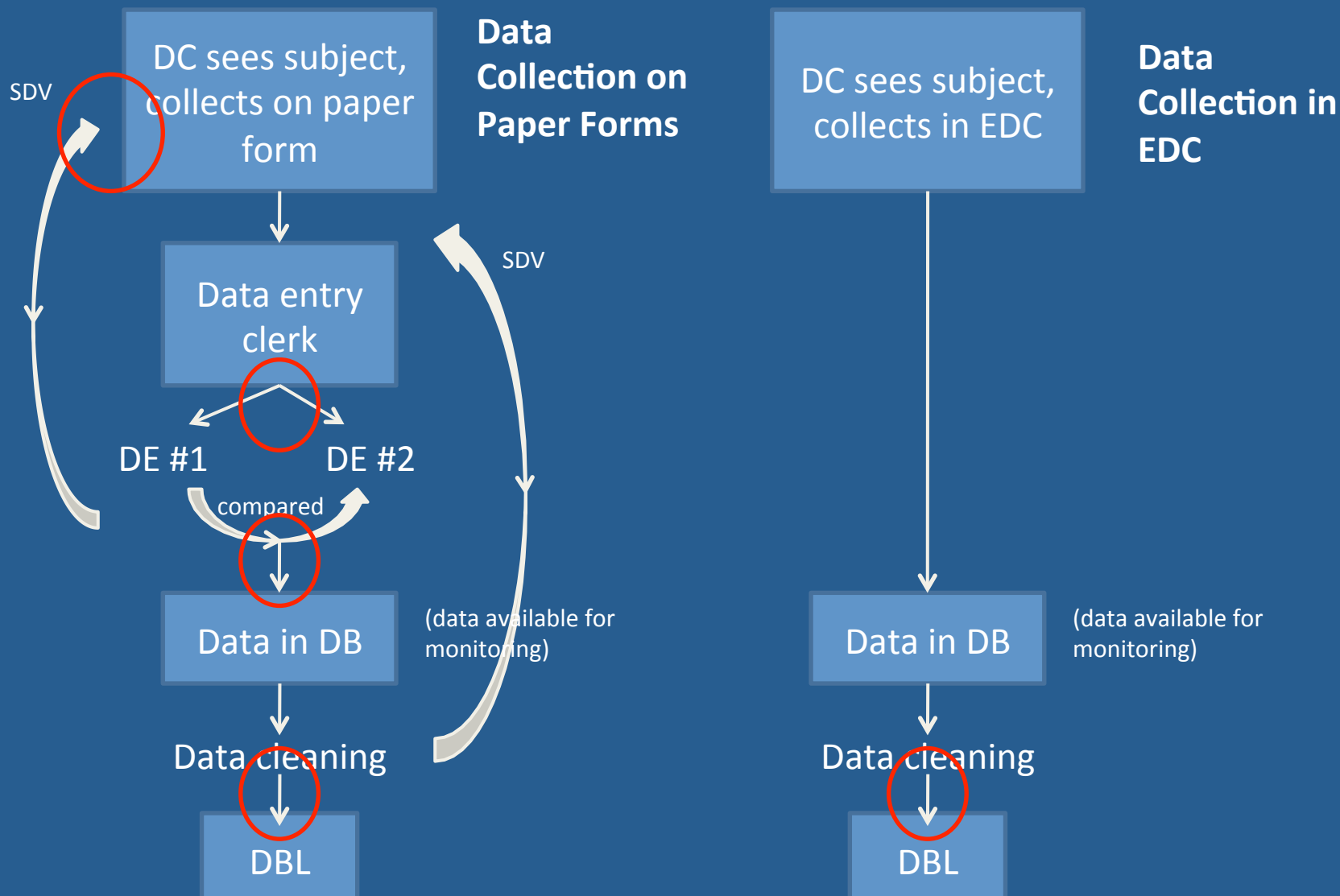
- Paper forms traditionally used
- Data manually entered into databases for aggregation and analysis
- Need for more human resources, double data entry, money, storage of paper forms....



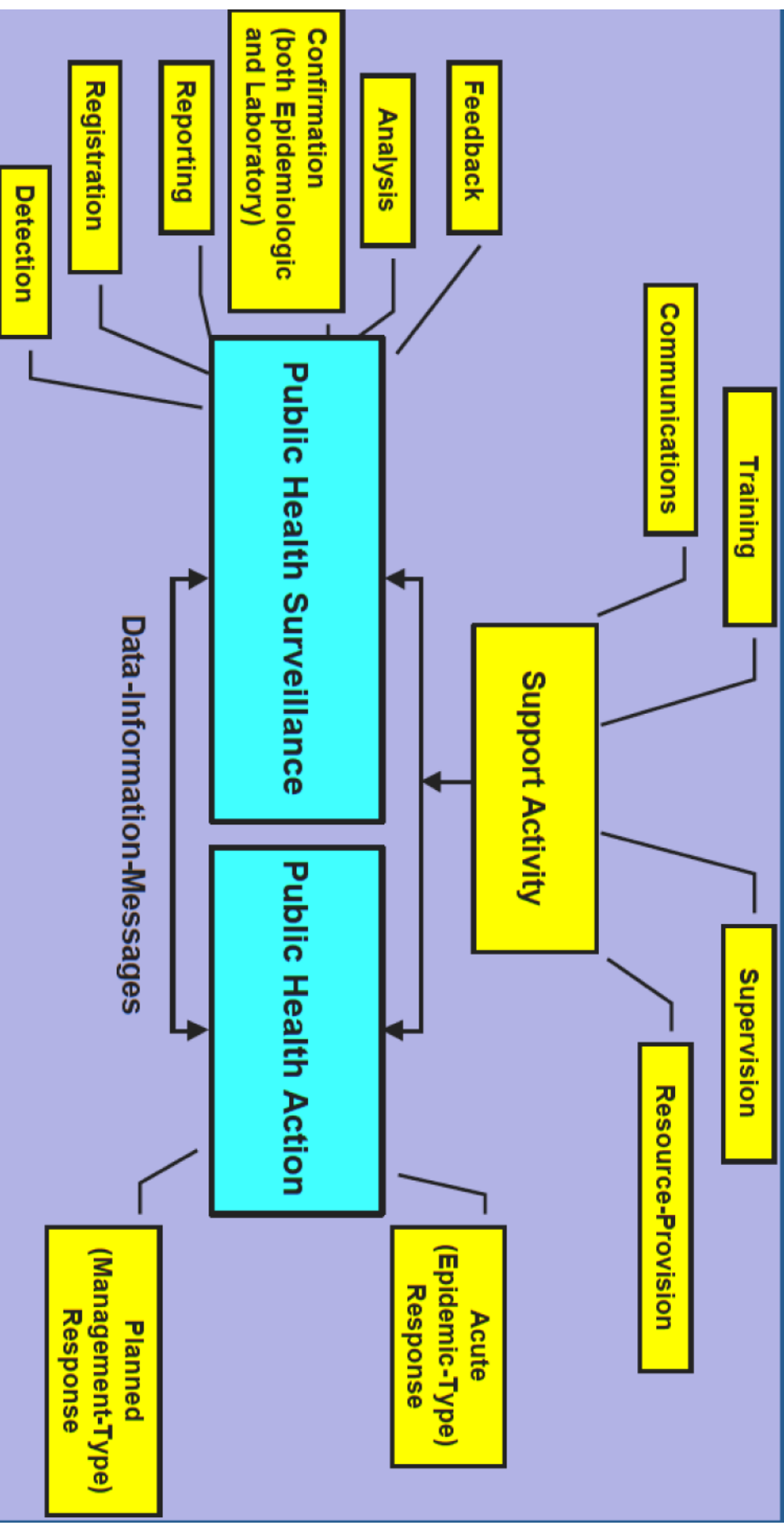
It has taken you so much time that someone else has already done the same study and published before you!

The Road to Database Lock

How many toll booths do you have to pass?



Surveillance: Complicated but Critical



Internet Based Surveillance Tools

- Global Public Health Intelligence Network (GPHIN)
 - Internet based early warning system, 7 languages, uses media sources, newsfeeds, websites etc
- Program for Monitoring Emerging Infectious Diseases (ProMED)
 - Internet based disease tracking, disseminates information by emails and posting case reports
 - Case reports linked with HealthMap
- Other Digital Disease Detection Resources



HealthMap

Global Health, Local Knowledge

- Led by the Computational Epidemiology Group at the Children's Hospital Boston Informatics Program
- Aggregates and maps data through mining of online news, official and unofficial reports and consumer reporting
- Disseminates information geographically online and through social media in 9 languages
- First outbreak phone app developed
 - www.outbreaksnearme.org

Brownstein J et al Digital Disease Detection – Harnessing the Web for Public Health Surveillance
New England Journal of Medicine 2009 360:21; www.healthmap.org

Global
Local
News

About
Projects
Mobile
Donate
Feedback
English

Search

Display Options: Map Satellite

Outbreak Missing? Add it to the map

Activity Index: Low High | Country level | Province or local level

Alerts from past week | **Avian Influenza (past month)** | **Drought in Africa 2011**

Quick Views

Putucherry

4 Nov - 47 dengue cases reported at govt hospital in 1 month - IBNLive.com

Date: 30 Oct - 07 Nov | Diseases: all | Places: all | Sources: all | Categories: all

Source	Date	Summary	Disease	Location	Cases	Deaths	Significance
	6 Nov	West Nile virus confirmed in Polk County (Wisconsin, United States)	West Nile Virus	Wisconsin, United States			★☆☆☆☆ 1 vote
	6 Nov	PRQ/AH/EDR> Rabies - USA (10); veterans, alert	Rabies	United States			★★★★★ 1 vote
	6 Nov	PRQ / ESP> Rickettsioses suspected cases - Mexico (Mexico)	Rickettsia	Mexico			★★★★★ 1 vote
	6 Nov	PRQ/EDR> Japanese encephalitis & other - India (32); (MA)	Japanese Encephalitis	Massachusetts			★★★★★ 1 vote

Using Phones for Surveillance

- Dengue Fever Monitoring in Mexico
 - Field members visit households and report cases immediately¹
- Real-time outbreak reporting in mass gatherings
 - Hajj 2009 used cell phones for surveillance²
- Reporting on endemic diseases (AESSIMS)
 - Front line workers report Japanese Encephalitis incidence through telephone and web-based technology in Andhra Pradesh³
- Emergency Reporting system for Infectious Diseases after earthquake in China⁴
 - Landlines and internet connections down, immediate move to SMS messaging of outbreaks

Jumping on the Bandwagon...

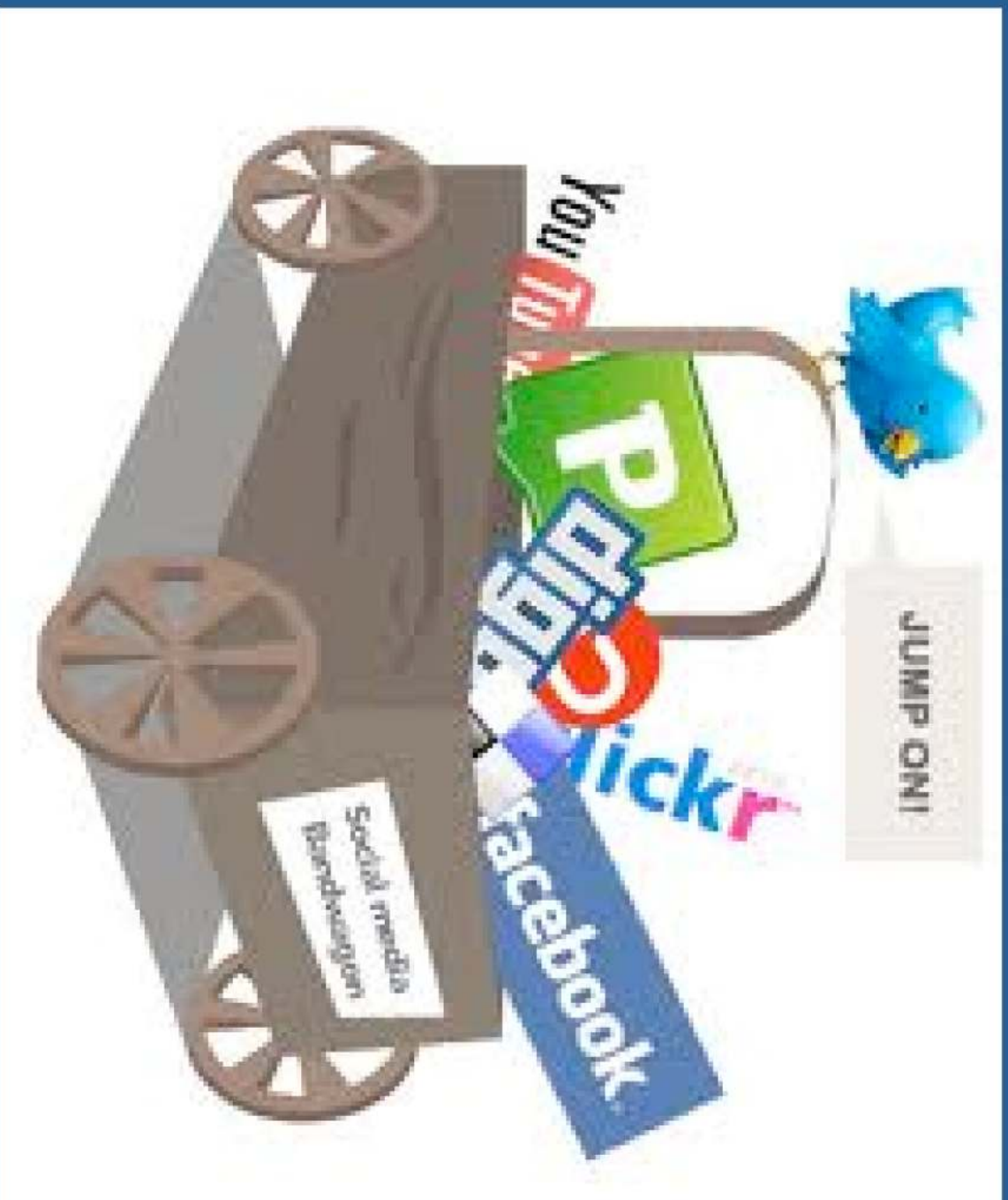
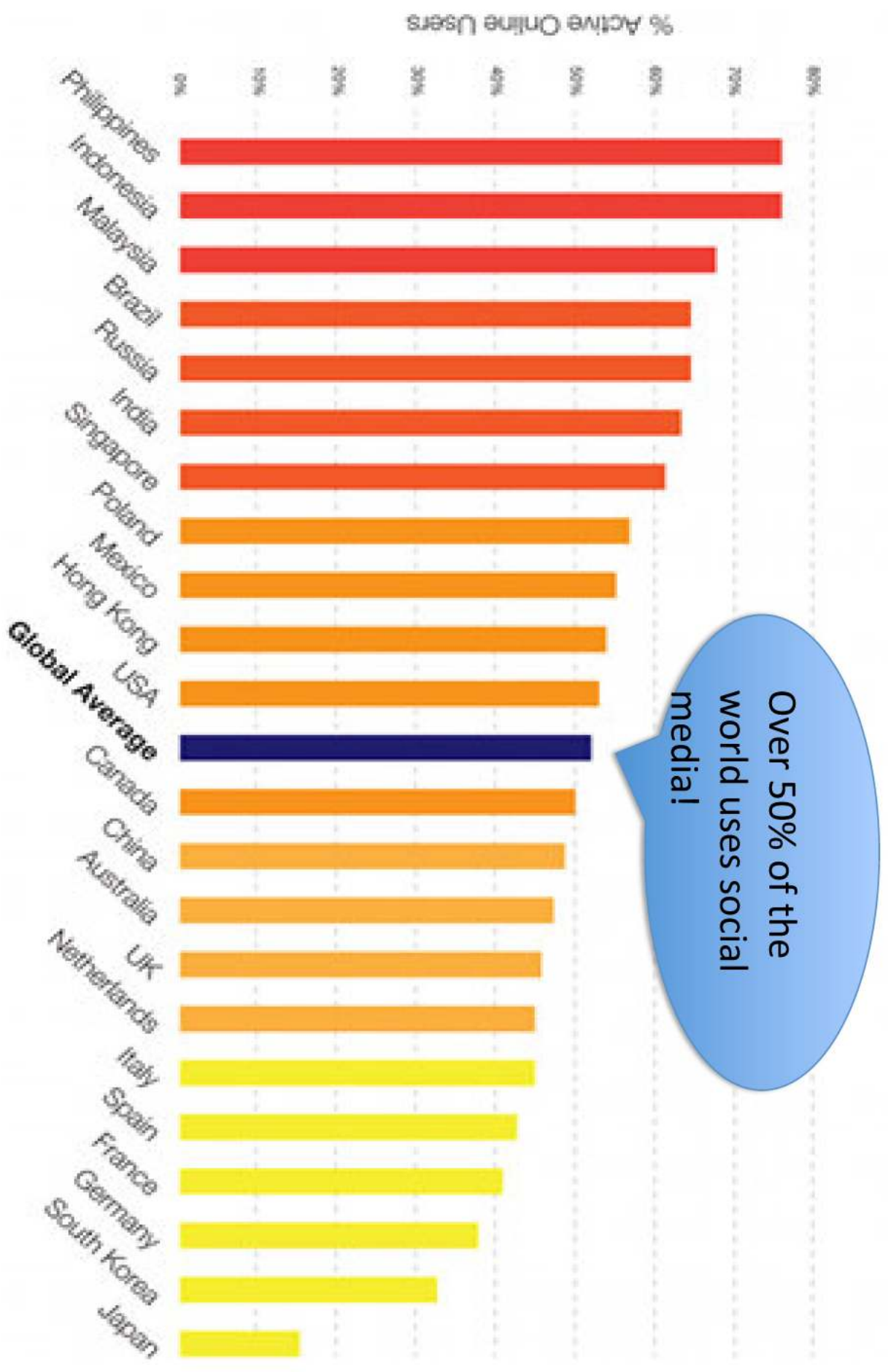


Image Courtesy of stanford.edu

Global Social Network Penetration



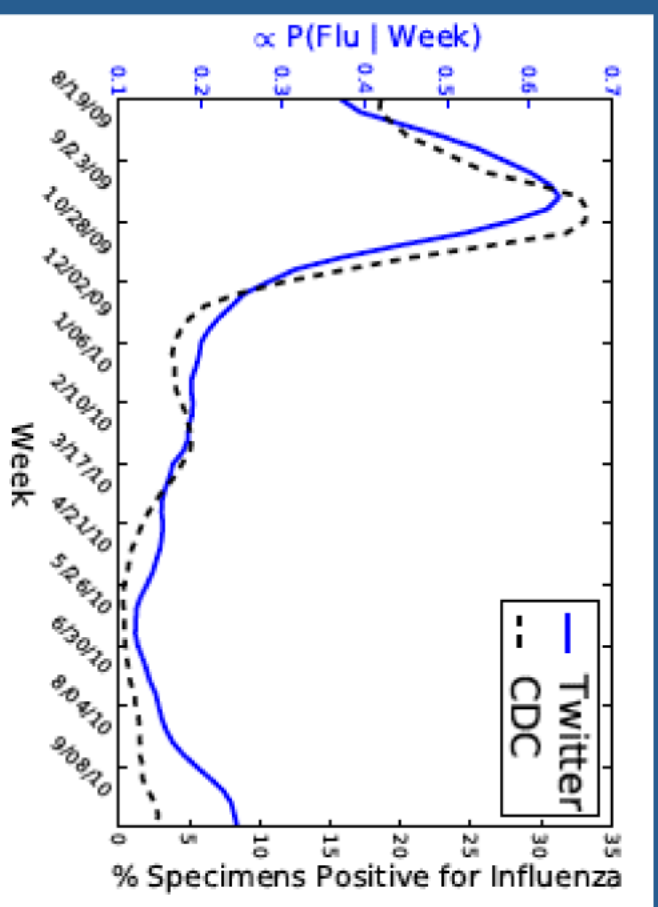
Social Networking and Syndromic Surveillance

Twitter¹

- WHO used twitter during H1N1 pandemic and had >11,700 followers
- CDC has 420,000 Twitter followers

Facebook

- Public Health Agencies share public health news and program information



¹ Christine McNab, WHO <http://www.who.int/bulletin/volumes/87/8/09-066712/en/>; ² GRAPH Source: Paul et al; You Are What You Tweet: Analyzing Twitter for Public Health, 2011; Association for the Advancement of Artificial Intelligence 39

“Participatory Surveillance”

- Citizen Science Model¹
 - Concept that citizens are willing to share health data for the greater good
 - Ripe opportunity to utilize Social Networking and media sites
- Can we tap into these networks for syndromic surveillance, programs and research?

¹ Weitzman et al; (2011) Sharing Data for Public Health Research by Members of an International Online Diabetes Social Networking site. PLoS One 6(4); Kahn et al; Mass Gatherings: Infections Disease Surveillance and Modeling across Geographic frontiers and scientific disciplines; Lancet In pres

- ‘Facebook-like’ forum for people with diabetes or loved ones with diabetes >20,000 members
 - Hosted by Diabetes Hands Foundation, supported by Children’s Hospital Boston Informatics Program
- Personally controlled Health Record (INDIVO) and user selects level of data sharing within the community
- Users can elect to participate in research studies

Research Immediately Influencing Policy

- TuDiabetes Survey developed in collaboration with the FDA to assess adverse events related to diabetic devices
- Goal:
 - Supplement FDA adverse events reporting system to improve consumer reporting
 - Explore avenues for education and dissemination of key diabetic device related events direct from the FDA to the consumer

Little over **one week** after survey launch
over **200** respondents, data analyzed
and results blogged in Wall Street Journal

THE WALL STREET JOURNAL.

Today's Paper ▪ Columns ▪ Blogs ▪ Topics ▪ Journal Community

Home U.S. World New York Business Markets Tech Personal Finance Life &

powered by  one spot

Early TuAnalyze Survey Results Show Members Having Serious Problems with Devices

(Posted on Featured Blog Posts - TuDiabetes at Wed, Nov 02, 2011 at 03:21AM)

Considerations and Benefits of m/eHealth



IT and Public Health Working Together

- Information technology experts and public health experts may not speak the same language
- Technology can complement public health surveillance and programs but should be a means to an end, not an end itself

Key considerations for implementing eHealth and mHealth interventions

- Familiarity of technology at all levels
- Accessibility of power, internet, technical support at all levels
- Use of mHealth for the right data collection or programmatic reasons
- Open source vs. proprietary software systems

Rewards of mHealth

- Real-time data collection, processing and analysis
- Accelerate interventions to prevent further morbidity or mortality
- Strengthen accuracy and timeliness of reporting
- User-friendly, portable and can be used in remote areas

Learning from Each Other

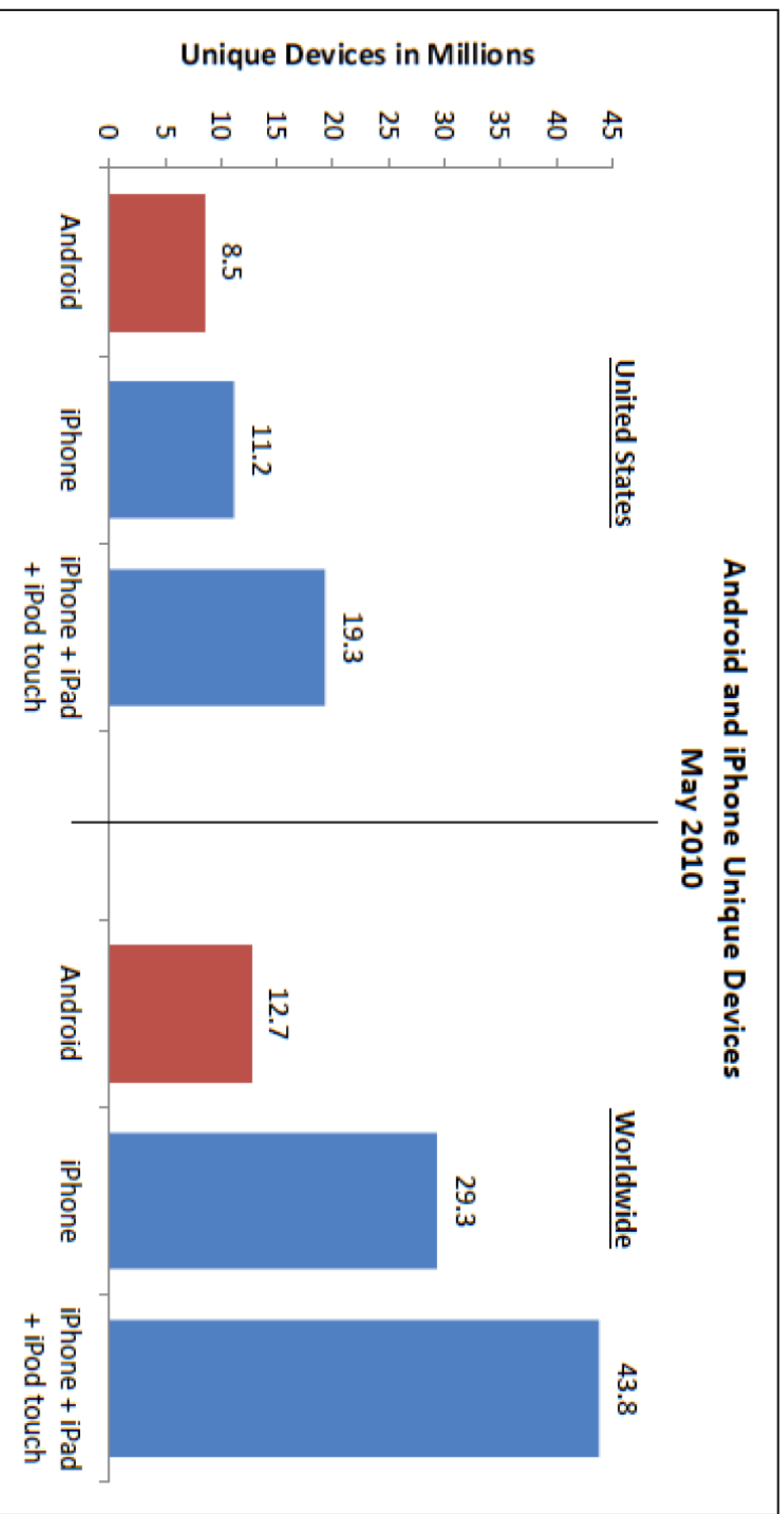
We would like to invite participants to share their experiences working with m/eHealth

We are also open to questions

Finally, thank you for attending this webinar!

Reserve Slides

The next wrestling match? iphone vs. Android



mHealth Resources

- mHealth Alliance (www.mhealthalliance.org)
 - Policy research, advocacy and support for mHealth initiatives
- mHealth in Resource-Poor Settings: Royal Tropical Institute (www.mhealthinfo.org)
 - Up-to-date source of information on ongoing mHealth projects

Sharing Data for Public Health Research by Members of an International Online Diabetes Social Network

Elissa R. Weitzman^{1,2,4*}, Ben Adida^{1,3}, Skyler Kelemen¹, Kenneth D. Mandl^{1,3,4,5}

