

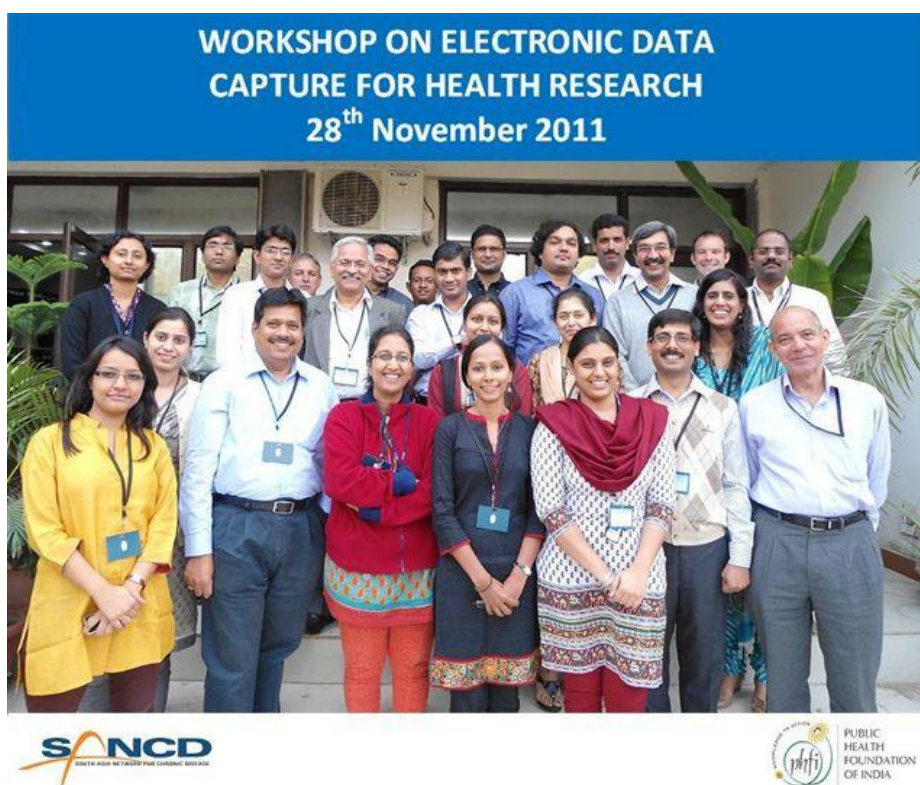
## WORKSHOP REPORT

### ELECTRONIC DATA CAPTURE METHODS FOR HEALTH RESEARCH

Monday, November 28, 2011

9:00 am-5:30 pm

SANCD, PHFI New Delhi 110016



Report Prepared by  
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## **I. Background and rationale of the workshop**

The workshop was organized to discuss the range of electronic data capture (EDC) methods being utilized by the SANCD network for clinical and research purposes. Members of the SANCD network wanted to share experiences and expertise to explore the cost, feasibility and practicality of various options in the field – some were forced to explore new alternatives as manufacturers shifted to newer devices, while others were utilizing vendors to explore platform-independent solutions or experimenting with newer platforms and tools themselves. The workshop is well-timed given the increased affordability, accessibility and innovation of electronic data capture options over the past year.

After the annual meeting in April 2011, there was a consensus in the SANCD network to host an EDC workshop. All interested SANCD network partners were invited for an in-depth discussion of the purpose of a workshop, expected outcomes, a proposed structure and agenda, and the expected audience/participants. The following themes emerged from those conversations:

1. How to plan ahead for EDC in low-resource settings such as public health/research?
2. What is the range of EDC methods/tools available over time? How does one choose the best hardware and software for one's project?
3. Representation from vendors on different platforms on types and ranges of applications to discuss what is most suitable for public health research in the future.
4. Practical, hands-on experience would be invaluable.

## **II. Objectives and expected outcome of the workshop**

1. To discuss the various methods of electronic data capture, their strengths and weaknesses, challenges and solutions, as applied by members of the SANCD network.
2. To learn from members of the industry about EDC trends over time, and to discuss the various technologies and platforms that are feasible and practical.
3. To discuss relevant themes such as the importance of connectivity, benefits of real-time data capture, etc.
4. To have hands-on, practical experience with the different EDC software and tools employed by SANCD network partners.

The expected outcome of the workshop is an increased understanding across a range of technologies and platforms on how to implement EDC for health research according to the specific setting/needs of your research setting.

## **III. Salient themes of the workshop**

### **A. Advantages and disadvantages of electronic data capture**

Presenters and participants discussed the various advantages and disadvantages of electronic data capture systems arising from their research settings. Advantages include streamlining the data capture and data

integration process, better data monitoring and feedback to the field, increased efficiency and scalability, reduces storage space required, fewer data entry errors and less data fudging, a shorter time to analyze and publish data, the potential for interactive communication, GIS integration and individualized treatment/guidelines, and the ability to incorporate multimedia, such as pictures, audio & video to enhance the richness of data collected. Disadvantages include the lengthy (and often unpredictable) process of developing the software and pilot-testing, communication barriers between researchers and developers, hardware and software malfunctions, lack of technical expertise for long-term troubleshooting and maintenance in many research outfits, field worker resistance to switching from a paper-based data capture to an electronic one, (often) steep learning curves and the investment into tools that can become extinct as technology continues to evolve (eg, HP PDA's).

### **B. Choosing the best hardware and software**

The importance of a methodical and systematic approach for determining the best hardware and software was emphasized, driven by the study objectives, timelines, funds, functionality, ease of use and needs of a particular research team/setting. There is disagreement on whether choosing hardware or software first is more practical; one network partner is un-coupling the two by implementing a tool, PhoneGap, that works across a range of devices.

The advantages of the PDA (robust, durable, reliable, stable, good for structured questionnaires), Android phone (compatible with multi-media, open data source platforms), laptop (multi-purpose, accommodates multiple accessories/plug-ins, screen size, good for open-ended text) and tablet (screen size, touch pad, new Indian models at low prices) were discussed. The final choice of the tool will depend on considerations such as durability, cost, battery life, type of questionnaire, user-friendliness, use of accessories, requirements for connectivity, long term maintenance/availability of spare etc. All presenters agreed that enough time needs to be allotted for development and pilot-testing, and yet maintain the work as a time-bound project/contract.

### **C. Importance of intermediaries and communication**

The successful development of an electronic data capture system requires well-defined research objectives and field-based logistics that are clearly understood by both researchers and developers, particularly up front, and throughout the development process. Presenters from the research and private sector both emphasized this point, especially as miscommunication can cause considerable delays and ultimately a project's failure or success. Smaller research organizations benefit by having an intermediary who can communicate between researchers and programmers, as the back-end development, nuances and processes are poorly understood by researchers. Moreover, after an electronic data capture system is in place, the resources, in terms of time and personnel, need to be considered and allotted for troubleshooting and maintenance. Another problem is that technology of the highest standards is ubiquitous and expectations of software (by researchers, project managers and field workers) should be practical and realistic.

#### **D. Low-cost innovations being used in the field**

Open-source software, such as Open Data Kit (ODK), and other free data entry packages are compatible with various devices to allow low-cost electronic data capture across a range of budgets. Open-source software can provide a platform for companies to develop free (eg, CommCare by Dimagi) or low-cost solutions (eg, eCollect by HandsRel) to your needs. Some solutions are geared towards platform independence to reduce reliance on higher-cost devices (eg, PhoneGap by Data Template, XForms). Open-source software offers innovative, dynamic, self-enhancing options that are free and supported by a community of developers who believe in open access to an end product's source materials. The disadvantage is that you need the expertise to highlight, understand and troubleshoot when problems arise (there is not one person accountable for open-source software).

Indian and Chinese tablets have increased accessibility to this otherwise high-end niche product, and created new low-cost alternatives for electronic data capture in low-resource settings. While android phones offer GPS compatibility, they are costlier than the Java basics, which are still being under-utilized for their potential.

Dimagi highlighted the use of multimedia to facilitate data capture in rural areas by anganwadi workers with low literacy levels. CCDC and Data Template showed how risk stratification, customized management plans and decision-support systems can be integrated into software that is platform-independent. SNEHA showed the integration of GIS with field worker visits and data capture. HandsRel discussed bio-statistical calculators, speech- and hand writing-recognition systems, and other applications that add functionality to low-cost devices.

#### **E. Improved data monitoring and data management**

Electronic data capture allows for more immediate access to data, via on-line data entry or off-line data capture periodically uploaded to a central server/database. It can identify errors/problems in the field as they are occurring, through error checking, tracking of individual cases, checklists and decision support. This real-time access to data can lead to improvements in data collection procedures that can thereby enhance overall data quality. For example, interactive feedback loops between data monitors, project managers and field teams, enhances the quality of information collected from the field. Developing an EDC system usually requires pre-defining variables, types, valid values and skip patterns in advance, which also reduces data entry errors in the field. The time to initiate analyses is considerably shorter as a result of EDC, facilitating a faster start for data analyses. For multi-center studies, it is particularly useful for long-distance monitoring of field work and data entry as they are collected in the field.

### **IV. Summary of presentations**

The workshop consisted of 8 presentations and hands-on demonstrations by members of the SANCD network and by industry representatives that have worked with the network on various projects.

1. The welcome and introduction was given by Professor Shah Ebrahim, Director of SANCD. The first talk was delivered by Shashank Garg, CEO of HandsRel, who provided an overview of the trends in electronic data capture over the years and the unique features of EDC that have changed over time.

He discussed a paradigm shift that has resulted in consumer-driven change that is bottom-up, rather than top-down from large companies facilitated by ubiquitous access to telecommunications, social networks and the convergence of computing and communications in small devices. He discussed the potential for technologies in the future, including the enhancements to functionality/applications and near-field communication for a wide range of applications, including low-cost bio-probes/sensors.

2. Mr. Ganesh BS Babu from Aravind Eye Care system discussed the range of EDC methods that have been employed by their organization over the past several decades, including the use of laptops in the field as early as 1989. He heads an IT department that is housed within Aravind, and which has allowed him and his team to evolve their methods according to the needs of the institute and their increasing patient base. Their EDC methods are utilized in clinical practice, field-based research and hospital management solutions. His presentation emphasized the need for rigorous, robust and well-tested systems of data collection, processing, management and organization. The participants then had an opportunity to try the PDA's they are using in one of their projects.
3. Ms. Smita Naik from Sangath presented on the needs-based approach utilized to finalize their EDC method, which consists of a custom-made software called FlexiQ in combination with HP PDA's, which have been incredibly robust, stable and reliable in the field for over 7 years now. However, PDA's are being phased out by the manufacturer and they must explore new options that suit their research needs. She emphasized the need for a systematic approach to decide on the best EDC choice, with ample time provided for pilot-testing. She stated that the true potential of EDC is yet to be realized. Workshop participants then tested the PDA's on the Sangath software.
4. Dr. Preet Dhillon and Mr. Dilip Jha from SANCD described the chronic disease risk factor (CDRF) pilot study for testing electronic data capture methods using laptops and electronic forms developed by two different vendors, HealthChakra and HandsRel. They provided a research user's perspective of the software development process with a vendor as well as the strengths and weaknesses of each approach. They also discussed challenges encountered and potential solutions proposed during the process with lessons learned for future, including the importance of communication, well-defined research objectives and expectations, good timing and appropriate timelines, patience and creativity. Both software products were tested on laptops.
5. Mr. Sameer Maheshwari, CEO of HealthChakra provided an IT, business and developer perspective to the process of developing software for consumers. He showed the back-end logistics, resources, strategies, timelines and human resource personnel that are required for successful implementation. He reiterated the importance of clearly-defined objectives and expectations at the outset to help ensure a smoother and more successful project launch.
6. Mr. Ajay Vamadevan from CCDC and Anil Parakkad from Data Template discussed the development of decision-support software for diagnosing hypertension in the field using mobile phones and a solution called PhoneGap, which was developed by Data Template using open-source software and created to be platform-independent. In a local language, the software can calculate risk and provide immediate feedback to the field on individualized treatment/management plans. The CTO, Ajesh

Appukuttan also informed the group about various technical aspects. Participants tested the software on the Android phones.

7. Mr. Glyn Alcock and Ms. Sushmita Das from SNEHA described the cluster-randomized trial in which they are testing open-source software on android phones to conduct interviews in Mumbai slums. They developed the software themselves using Open Data Kit (ODK), which was unique given that they had no supporting IT infrastructure and no resources for outsourcing the task. Glyn led a demonstration of creating a survey/questionnaire on OKD and how to upload data from the Android phones to the server. Participants had an opportunity to enter and upload data from the Android phones.
8. Matt Theis from Dimagi closed the session with the range of innovations for mobile health, including mobile messaging systems, health systems architecture and mobile device applications. He discussed messaging solutions (eg, Zambia) that work across platforms (eg, Java, Android, Symbian); electronic health records with mobile, smartcard and web-based technologies; and mobile device applications for data collection or information sharing (eg, Karnataka). The range of these solutions is being applied by Dimagi in over 20 countries around the world.

#### A few glimpses from the workshop



## V. Useful websites on electronic data capture

Open Data Kit (ODK)	<a href="http://www.opendatakit.org">http://www.opendatakit.org</a>
CommCare / Dimagi	<a href="http://www.dimagi.com/commcare">http://www.dimagi.com/commcare</a> <a href="http://www.commcarehq.org">http://www.commcarehq.org</a>
OpenXdata	<a href="http://www.openxdata.org">http://www.openxdata.org</a>
GATHERdata	<a href="http://www.healthnet.org/gather">http://www.healthnet.org/gather</a>
OpenClinica	<a href="http://www.openclinica.org">http://www.openclinica.org</a>
FrontlineSMS:Medic	<a href="http://www.frontlinesms.net">http://www.frontlinesms.net</a>
Medic Mobile	<a href="http://www.medicmobile.org">http://www.medicmobile.org</a>
MobileActive.org	<a href="http://www.mobileactive.org/comparing-mobile-data-collection-tools-followup">http://www.mobileactive.org/comparing-mobile-data-collection-tools-followup</a>
Open Data Kit (ODK)	<a href="http://opendatakit.org/">http://opendatakit.org/</a>
KoBo Project	<a href="http://koboproject.org/">http://koboproject.org/</a>
Purcforms Form Designer	<a href="http://purcforms.appspot.com/FormDesigner.html">http://purcforms.appspot.com/FormDesigner.html</a>
XForms (Dimagi)	<a href="http://xforms.dimagi.com/">http://xforms.dimagi.com/</a>
MapCruzin.com	<a href="http://www.mapcruzin.com/free-gis-software-tools.htm">http://www.mapcruzin.com/free-gis-software-tools.htm</a>
Bryan R. McBride, GISP	<a href="http://bryanmcbride.com/fun-with-the-open-data-kit">http://bryanmcbride.com/fun-with-the-open-data-kit</a>
Emily Kumpel	<a href="http://ekumpel.wordpress.com/2011/02/13/135/">http://ekumpel.wordpress.com/2011/02/13/135/</a>
HealthChakra	<a href="http://www.myhealthchakra.com/myhc/">http://www.myhealthchakra.com/myhc/</a>

## VI. Workshop agenda

- 8:30-9 am: Registration & tea**
- 9 am:** Welcome by Professor Shah Ebrahim, Director of SANCD
- 9-9:30 am:** Electronic Data Capture Tools – An Overview and Some Future Trends  
**Shashank Garg (HandsRel)**
- 9:30-10 am:** Aravind: Spectrum of in-house developed EDC methods employed over the decades
- 10-10:20am:** **Discussion**  
**BS Ganesh Babu**
- Coffee & tea break**
- 10:30-11 am:** Sangath: Using PDA Technology in Research - Improved integration of technology into public health research
- 11-11:30 am:** **Discussion**  
**Smita Naik**
- 11:30-12 pm:** SANCD: Outsourcing and implementation of electronic data capture software: A (research) user's perspective for a multi-center study
- 12-12:30pm:** **Discussion**  
**Preet Dhillon and Dilip Jha**
- 12:30-1:30 pm: Lunch**
- 1:30-2 pm:** Software development for health research/settings from the developer's perspective  
**Prashant Tandon/Sameer Maheshwari (Health Chakra)**
- 2-2:30 pm:** CCDC: Decision-support software & individualized algorithms for hypertension management at primary care settings.
- 2:30-3 pm:** **Discussion**  
**Ajay Vamadevan (CCDC) and Anil Parakkad (Data Template)**
- 3-3:15 pm: Coffee & tea break**
- 3:15-3:45 pm:** SNEHA: Electronic data collection using open-source software and Android smartphones
- 3:45-4:15 pm:** **Discussion**  
**Glyn Alcock and Sushmita Das**
- 4:15-5pm:** Innovations for Mobile Health  
**Discussion**  
**Matt Theis (Dimagi)**
- 5pm: Closing**

## VII. List of participants and organizations

Name	Organisation	E-mail ID
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## Organizations represented

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### **HANDSREL**

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## **Organizations represented (con.)**

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### **HealthChakra**

Organization: HealthChakra, HealthKart

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