

# **Contextual Reality of Client Level Data Collection: Challenges and Technologically-Based Opportunities from California**

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# Issue

- The California Department of Public Health, Center for Infectious Diseases, Office of AIDS (CDPH/OA) supports
  - HIV Counseling and Testing (C&T)
  - Health Education/ Risk Reduction (HE/RR)
  - Partner Services (PS)
- More than 700 provider locations statewide have provided these activities.
- In 2007, data were collected from approximately 500,000 client contacts using multiple forms.

# Issue

- Most data is collected by provider staff via paper forms that require manual data entry.
- Reliance on staff and paper forms at high volumes results in
  - reduced data reliability
  - increased provider burden
  - reduced efficiency
  - greater overall cost

# Setting

- California has diverse client populations and venues.
  - Clinic size and volume
  - Venue settings (outreach, mobile, STD, etc.)
  - Client characteristics and populations
- Various contextual challenges to data collection
  - Variety of technical knowledge
  - Clinic flow

# Project

- Joint effort between the CDPH/OA, San Francisco Department of Public Health, and County of Los Angeles Public Health, Office of AIDS Programs and Policy
- Developed and implemented client level data collection pilot projects that utilize innovative technological solutions
- Convened a summit of technology innovators to conceptualize a technologically-focused platform

# Why Imperative?

- Reduce provider burden and redundant efforts
- Increase data accuracy and reliability
- Provide increased client privacy
- Reduce socially desirable reporting
- Remove data collection from client provider interactions

# Why Imperative?

- Scarce resources vs. programs growing
  - Decrease program costs and improve program efficacy
- Maximize clinic resources
  - Increase clinic volume by enhanced efficiency
- Integrate State and local systems to streamline and simplify data processes
- Enhanced responsiveness to change
- End or at least slow the revolving door for data requirements and procedures

# What is Needed?

- A technologically-focused solution that
  - Is a single web-based platform operational across all settings
  - Supports paper-based and technological data collection in a streamlined and efficient manner
  - Addresses multiple needs without multiple packages (e.g., C&T, HE/RR, outreach, linkages to care and partner services, lab data)
  - Supports automated procedures to receive data from outside sources (e.g., labs and hospitals)
  - Responsive to expanding programs and partners
    - Connect and retrieve data from new systems

# What is Needed?

- A technologically-based solution that
  - Supports multiple devices (e.g., PDAs, cell phones, touch screens, scans)
  - Uploads data directly to a centralized web-based system
  - Allows point of contact (POC) provider access to data
  - Secure and compliant with ADA and HIPAA requirements
  - Is user friendly, multi-lingual, and cost effective
  - Has adequate technical assistance and quality assurance resource needs

# Technology Summit

- October 29, 2008; Newport Beach, CA
- Participants
  - AIDS service providers
  - Those developing and piloting technology
- Purpose
  - To discuss data collection challenges
  - Pros/cons of various technologies that address these challenges

# Technology Summit Goals

- Learn about technological replacements for
  - Staff-administered paper based data collection
  - Manual data entry
- Learn about technological solutions
  - Data linkage
  - System integration
  - Remote or external partner data transmission

# Technology Summit Goals

- Gain insight into best practices and experiences and their limitations
- Identify solutions that address clinic capacity and client characteristics
- Begin to conceptualize a State plan that integrates a variety of technology platforms

# Data Collection Technology

- Computer Assessment and Risk Reduction Education (CARE-Tool)
  - Client self-administered prevention tool using an audio computer-assisted interface via tablet PC or kiosk
  - Dynamic interactive program that assists clients in developing a personalized HIV risk reduction plan (Project RESPECT 2 counseling protocol)
  - Data automatically sent to a central server (encrypted wireless)
  - Can be used in waiting rooms, mobile vans, and outreach
  - Different versions (rapid testing, medication adherence counseling, PEMS-compliant, online version, Spanish)
  - Designed by Freya Spielberg and Jim Larkin ([www.ronline.com/care](http://www.ronline.com/care))

# Data Collection Technology

- PalmIT
  - Client self-administered HIV counseling and testing risk assessment via computer or handheld PDA
  - Comprehensive data collection which eliminates multiple forms and includes HIV lab test results.
  - Encrypted data is uploaded to a secure server.
  - Developed in collaboration between the San Francisco Department of Health, Office of AIDS and UCSF Center for AIDS Prevention Studies (CAPS)
  - More details coming up next.

# Data Collection Technology

- JavaROSA for mobile data collection
  - Used in Sub-Saharan Africa
  - Quick forms can be developed and used on Java cell phones or PDAs
  - Yes/No questions and skip patterns
  - Open source code
  - Possible use in rural communities
- Scanning Technology
  - Reduces keyed data entry and staff resources
  - Portable scanners can be used in the field
  - Advances in scanning technology

# Key Questions

- How to ensure the technology does not cause a backlog of clients?
- Impact on site operations/procedures
- Affordable and feasible for settings who see fewer than 10 clients/month?
- How to integrate with other systems (care and treatment, medical facilities, etc.)?
- How to identify and track individuals in the system without using any personal information?
- Security and confidentiality

# Benefits

- Link unique client data at point of client contact
- Reduce data collection from client-provider interactions
- Provide technological driven client risk reduction plans and referrals
- An integrated system

# Challenges

- Ensuring client privacy/confidentiality
- Provider and client technical skills
- Language barriers
- Vandalism and theft of equipment
- Data transfer to server
- Adequate staff to assist
- Technology and clinic flow

# Challenges

- Local flexibility vs. data consistency
  - Different data needs
  - Data compatibility
  - Clinical information systems (CIS)
  - Common data structure (HL7)
  - Information exchange / development of a common interface
- Scalability
  - Reducing the “digital divide”
  - Laying the ground work

# Results

- Clients' experience is improved by
  - Increasing privacy
  - Reduce data collection from client-provider interactions
  - Empowering clients to use technology
- Among local and county agencies
  - Reduced data collection burden and redundant effort
  - Greatly reduces keyed data entry
  - Maximizes clinic resources in a time of reduced resources and expanding programs.

# Lessons Learned

- Provide ease of use for clients and providers.
- Local flexibility
  - Supplemental data at the provider level, not at the State level
- Support multiple data collection methods (handheld devices, scanning, cell phones, informational kiosks, and paper)

# Lessons Learned

- Integration with existing systems such as electronic medical records or electronic laboratory records.
- Confidential data linkage across services at the point a client initiates receipt of services.
- Scalable and responsive to change
- Address requirements instead of a focus solely on the desired solution.

# Upcoming Presentations

- Real examples of how technology is being used to improve services
- What works and challenges for implementation
- Later you will hear about a conceptual diagram to collect data electronically throughout the state of California.

# Contact Information

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