

**Final Evaluation Report
Access Community Health Network
TOP - Technology Based Adherence Project**

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Produced by



Metro Chicago Information Center
17 N. State Street, Suite 1600
Chicago, IL 60602
www.mcic.org
(312) 580-2878

Overview of Project

Access Community Health Network established the West Side Collaborative Care (WSSC) in response to the identified need for an integrated, networked service delivery system on Chicago's West Side. The collaborative represents three community health providers, one AIDS services organization, one community-based organization and two drug treatment providers.

The WSSC Technology Opportunity Program - Technology Based Adherence Project (TOP-TBAP), funded through the U.S. Department of Commerce, is a project with a two-fold purpose: to use web-based and wireless technology to facilitate referrals and information sharing among participating collaborative agencies and increase client adherence to treatment plans. TOP-TBAP is expected to impact both the clients enrolled in the technology study and the collaborative agencies developing and using the technology.

The project was expected to result in improved patient access to multiple agencies for treatment services, improved patient adherence to referrals and treatment plans, and the creation of a coordinated service delivery and support system among the agencies and their consumers to improve the overall health of patients and their communities. Specifically, the goals of the project include:

- (1) A 30% increase in the number of patients completing inter-agency referrals among the partner organizations.
- (2) 75% of the patients who receive the pager technology will demonstrate improved adherence to their medication and treatment plans.

In addition, the evaluation of this project will take into account the impacts of the project on participating agencies and the satisfaction level of both patient and agency end users of the technology.

The implementation of the project went mostly according to plan, though there were some delays in the timeline and modifications to the technology selected due to challenges in customizing the software, the limitations of the hardware, and the preferences of clients who participated in focus groups.

Evaluation Design

Access Community Health Network hired MCIC (Metro Chicago Information Center), an independent non-profit research and consulting organization, to conduct the process and outcomes evaluation of the TOP-TBAP project.

The evaluation design of the TOP-TBAP project included qualitative and quantitative components. The findings from the qualitative elements of the evaluation (focus groups with clients on their technology preferences, concerns about the project, and how the project impacted them; and two series of key informant interviews with impacted staff members at participating agencies) shaped some of the technology and training decisions made during the course of the project and informed the conclusions in the final section of this report.

The quantitative element of the evaluation was designed to rely on objective, verifiable data rather than only using subjective or client-reported data. Through summer, 2002 each agency worked with MCIC to determine the specific client populations they would target with the services their agency could provide. Clients were selected based on the criteria refined by each agency, balancing the desire to target specific subpopulations that were thought to potentially benefit the most with the need to keep inclusion criteria broad enough to ensure an adequate number of participants. Objective measures were laid out for each agency, designed to measure the impacts of that agency's interventions on the target population they selected.

The original goal was to involve 100 clients who would all receive pagers and then to measure the changes in their risk behaviors and adherence before and after clients received the pagers. In order to distinguish the effects of the pagers from the effects of simply receiving standard services, the targeted number of participants was increased to 150, with 100 to be randomly assigned to the experimental (pager) group and 50 randomly assigned to the control (standard services) group.

The original lists of clients to be enrolled in the study were compiled in late fall 2002, and agencies were asked to have clients sign the informed consent form approved by the Mount Sinai Hospital IRB to permit elements of their demographic and treatment information to be shared with agencies participating in the WSCC TBAP project. Agencies were to collect data in two ways: through the web-based *Equicare* system and using paper Objective Data Collection sheets. The *Equicare* system prompted providers to complete 22 assessment questions quarterly and when making any referral through the system and to complete a 13-question Indicator Panel every 90 days.

The hard-copy Objective Data Collection Sheets contained measures specific to each agency to be collected over four three-month periods during the study. The first two data collection periods, which covered January 1, 2003 through March 31, 2003 and June 1, 2003 – August 31, 2003 were intended to secure a baseline measurement for future comparison. The subsequent data collection periods, which originally were to cover the same time periods in 2004, were intended to measure the impacts of the pagers, scheduled to be deployed in fall 2003. Due to delays in rolling out the pagers for the adherence module, the third data collection period was pushed back a month to February 1, 2004 through April 30, 2004. In order to ensure adequate time for analysis, the final data collection was moved up one month to May 1, 2004 – July 31, 2004.

Participation levels were lower than planned. Fewer study participants were recruited than were called for in the study design, and a higher percent of them than anticipated dropped out during the course of the study. In order to maintain a sufficient number of study participants to allow for a statistical analysis of the outcomes of the intervention, agencies were encouraged to make every effort to explain the benefits of the project to clients who were contemplating dropping out, to reach out to clients who were difficult to contact, and to replace study dropouts. Study dropouts were replaced with alternate clients for whom the objective data measures could be reconstructed for at least one of the pre-intervention periods using agency records.

Despite these efforts, only 96 clients were included in the final data analysis. Of these 96 clients, only 74 had three or more sets of objective data recorded; 42 had at least one quarterly assessment recorded, and 46 had at least one indicator panel recorded. Only 31 clients have three or more objective data recordings, at least one quarterly assessment, and at least one indicator panel.

Findings

The criteria used by each agency to define their “at-risk” population varied; the table below shows the population identified by each agency.

	Access Community Health Network	Genesis House	Haymarket Center	Lawndale Christian Health Center	PCC Community Wellness	Vital Bridges
Target Group:	Male IDU's Female IDU's MSM's	Women in recovery	Hepatitis C-positive drug users HIV+ Post release HIV+ substance users	HIV+ Substance Abusers	Substance Abusers with chronic asthma, physical or psychosocial issues	HIV+ Adults
Number Enrolled:	7	12	18	6	7	41

Five additional clients participated in the study at some point, but no agency submitted objective data for them. However, the quarterly assessments and indicator panels completed for these clients are included in this analysis.

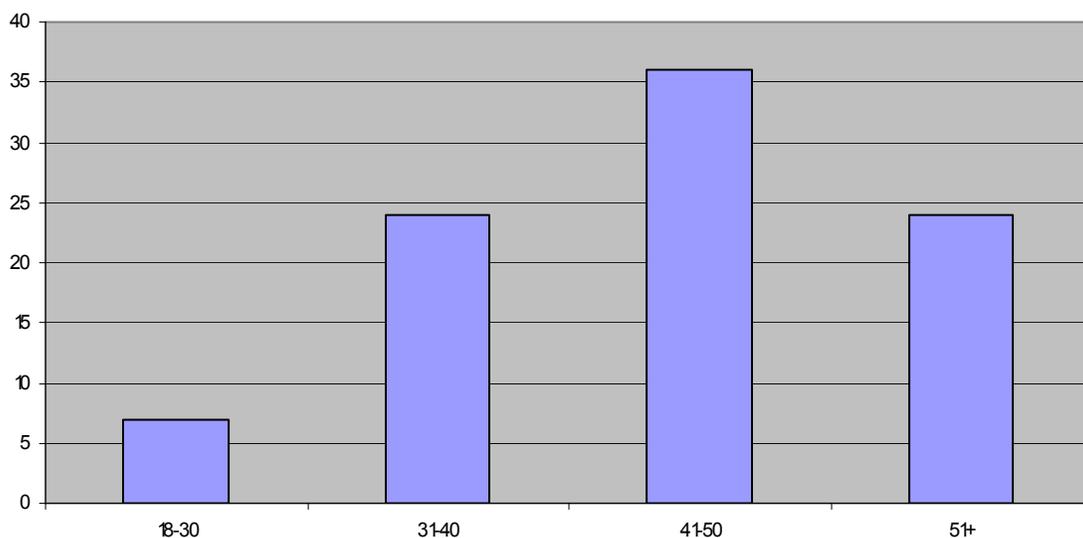
Initial Client Characteristics

The data presented in this section represent a baseline from which to measure changes in client risk behaviors and adherence. The data come from a variety of sources, including the indicator panel and assessment questions in the *Equicare* system, the WSCC identification numbers, and the Objective Data Collection sheets. The next section assesses the level of agreement among the indicators from these various sources.

Demographics

Fifty-eight percent of clients were male and forty-two percent were female.

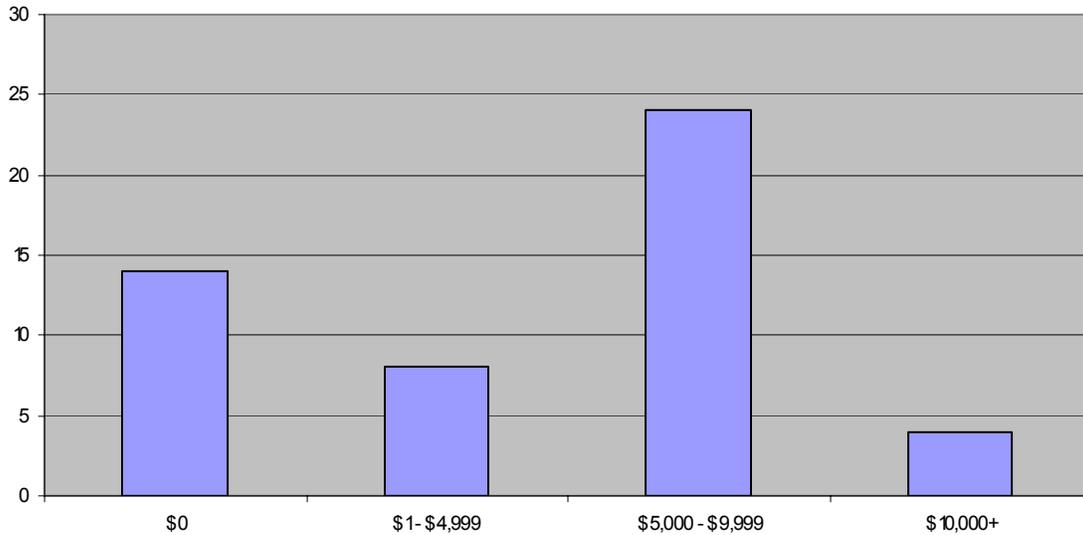
Age Distribution of Clients



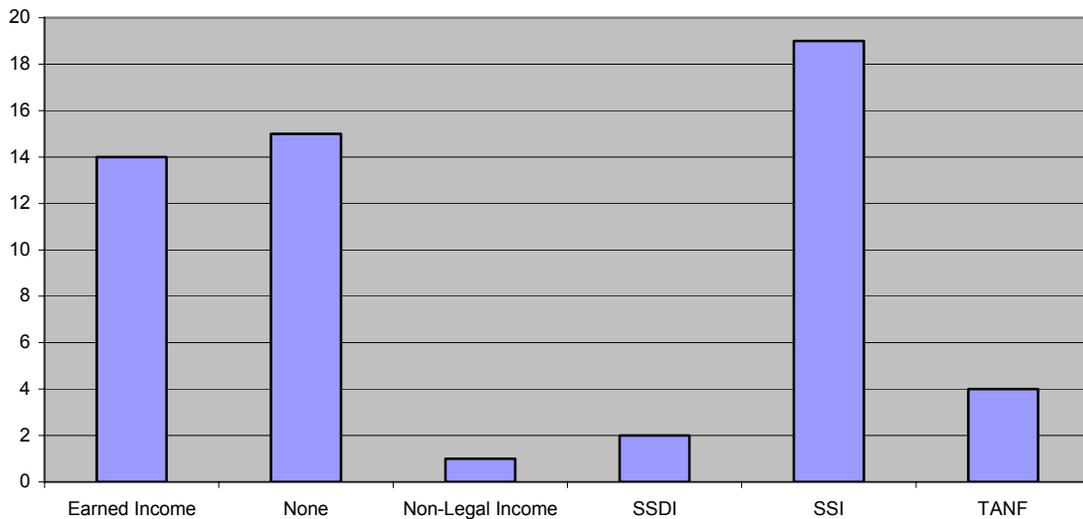
The mean age of clients was 43.4 years, and the median was 44 years. The chart above shows the distribution of clients by age group. On the whole, the clients enrolled in this study were generally older than the population of the communities served by participating agencies.

Annual income was recorded in two questions in the quarterly assessment. The first question asked clients, "Approximately, what is your yearly income?" A total of 43 clients answered the assessment questions, giving a total of 55 responses over the course of data collection. The breakdowns of responses to this question, and the second income question, "What is your source of income?" appear in graphs on below.

Yearly Income



Income Sources of Clients



A total of 66 of the 96 clients (69%) for whom data were recorded are known to be HIV positive. The majority of these are clients at Vital Bridges, an agency whose mission it is to serve people with HIV and that selected HIV-positive adults as their at-risk target population.

Seventy-one percent (30 of 42) of clients for whom at least one quarterly assessment was completed reported some disability, either HIV/AIDS (27), Mental (1), or Physical (3).

Thirty-seven of 42 clients for whom at least one quarterly assessment was completed (88%) report currently taking some sort of medication. The most common are medications for HIV, reported by 27 clients in their initial assessment. Eighteen reported taking medications for other medical conditions, and three for psychiatric conditions.

Only one client is a veteran, and she is among the eleven of 42 clients who reported having insurance in their responses to the assessment questions. Thirty-one of 42 (74%) clients with at least one completed quarterly assessment were uninsured.

Sixty-two percent (26) of respondents who completed at least one quarterly assessment have at least one child. Of these, eight (31%) have custody of one or more of their children. Five clients reported that DCFS is involved with the custody of their children; four of these clients did not report currently having custody. Five women reported being pregnant at the time of their assessments.

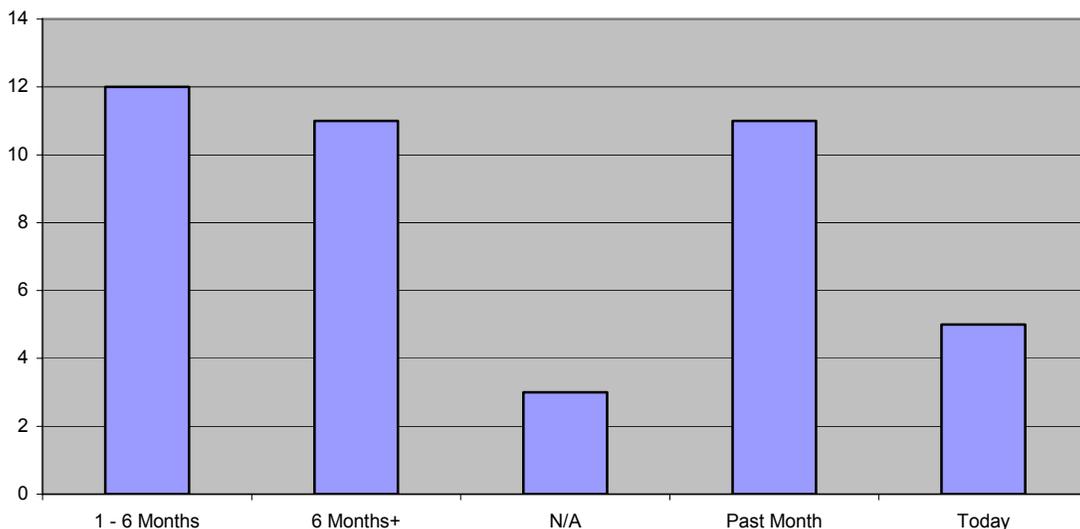
Risk Factors

A number of indicators capture information about risk factors that increase the probability that clients will struggle to maintain lifestyles that support their health and well-being. These include drug use, sex work, domestic violence, and homelessness.

Many of the clients involved in the study have a history of drug use, are currently using, or are actively confronting their addictions. All the agencies except Vital Bridges specifically selected substance abusers or people in recovery for their target populations.

There are several indicators that measure drug usage. Clients were asked their drug of choice and the date when they last used their drug of choice as part of the subjective quarterly assessment. These dates were recoded to show the time since the client last used their drug of choice and are presented in the chart below.

Last Time Client Used Drug of Choice

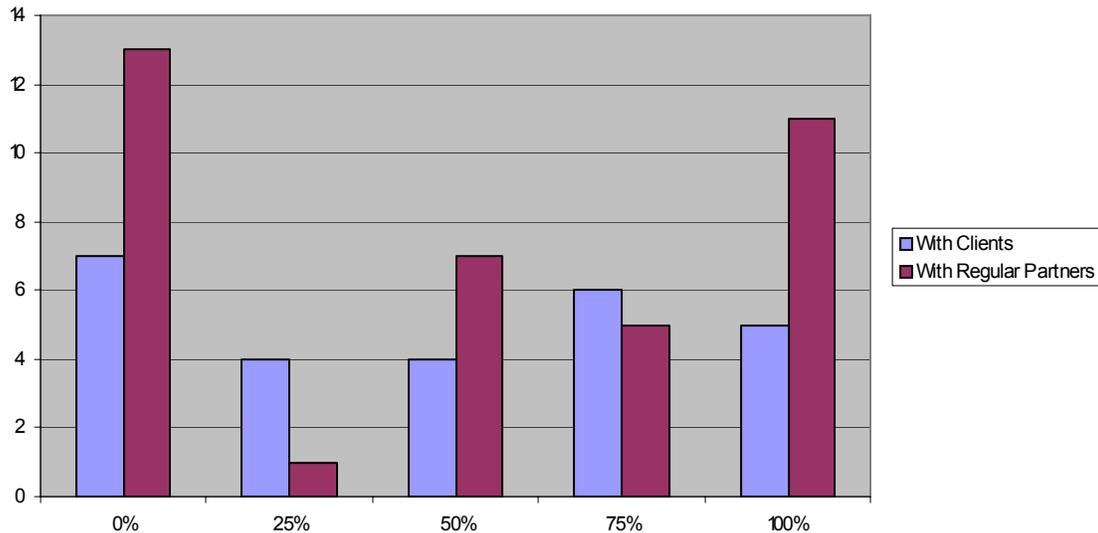


Thirteen of 42 clients who completed at least one quarterly assessment reported being an injection drug user. Of these injection drug users, two reported that their drugs of choice included alcohol, six cocaine, four crack, eight heroin, and one methadone. Respondents could report more than one drug of choice.

In addition, two agencies, Genesis House and Haymarket Center, collected objective data to document drug use. Thirteen clients of the thirty affiliated with agencies that recorded drug test results on their Objective Data Collection sheets had positive drug test results recorded at some point during the course of the study. Among those who tested positive for drug use during the study, one (8%) reported using her drug of choice on the day of her first quarterly assessment; three (25%) reported using their drug of choice within one month of their first assessment; three (25%) within one to six months of their first assessment, and five (42%) reported it had been more than six months since using their drug of choice at their first assessment.

Eight clients among those for whom there is at least one completed quarterly assessment (42) or indicator panel (46) reported exchanging sex to get drugs, money or shelter in the past 90 days. Five of these sex workers were female, and three were male. Together, they reported a total of three to six female partners and 33 – 45 or more male partners in the 90 days preceding their first indicator panel. Sex workers reported a range of practices with regard to frequency of condom usage with clients and with their regular partners. One of the eight reported never using condoms with clients, and one reported always using condoms with clients. Two reported using condoms with clients about 25% of the time, and three reported using condoms with clients 75% of the time. Condom usage with regular partners also varied, with two reporting never using condoms with their regular partner, three reporting using condoms about 50% of the time, and one each reporting using condoms with their regular partners 75% of the time and 100% of the time. Condom usage patterns for all respondents who completed at least one indicator panel appear in the chart below.

Condom Usage in Past 90 Days



Twelve clients indicated in their initial quarterly assessment that they were victims of domestic violence.

Five clients were recorded as homeless according to their initial quarterly assessment, and two more were recorded as homeless in objective data submitted by Haymarket Center.

Agreement Between Indicators

By design there are some significant overlaps among the three data sources contributing to this analysis, but not every measure of client lifestyle, risk behaviors, and adherence to treatment plans appears more than once. A number of elements are each represented by only one indicator.

Several of the overlapping indicators of drug use and risky sexual behavior were presented in the preceding pages. Indicators of risk behavior from different sources did not agree all the time for all the clients. Much of this inability to confirm the data from one set of indicators with data from another set was due to the incompleteness of the data. Agencies did not submit Objective Data sheets for all the clients for whom they completed at least one quarterly assessment or indicator panel, and they did not complete quarterly assessments or indicator panels for all the clients for whom they completed Objective Data sheets.

There are more overlaps among the three sets of indicators for elements relating to adherence than to risk behavior. These overlaps are intended to enable the verification of self-reported data in the indicator panel and the assessment questions with objectively measured data.

For example, both the indicator panel questions and the majority of the Objective Data Collection sheets record missed appointments in the past 90 days. After matching the Indicator Panel question by date to the relevant objective data collection period, it is possible to assess the level of agreement between the two indicators. Of the 22 clients for whom the indicator panel was completed between July 17, 2003 and January 28, 2004 (all of which dates would most closely reflect the conditions measured during the second data collection period, June 1, 2003 – August 31, 2003 for all the agencies except Genesis House, which collected data for September 1, 2003 – November 30, 2003), the responses to the Indicator Panel question “Have you missed any appointments with case managers or doctors in the past 90 days?” matched the objective data recorded on the number of appointments scheduled versus the number of appointments kept as scheduled for 18 of them, or 82% of them. Given that there are slight differences in the exact indicator being measure by each question, this high level of agreement is reassuring.

Both the Indicator Panel and the objective data recorded by Lawndale Christian Health Center and PCC Community Wellness include the number of ER visits in a 90-day period. In this case it is difficult to compare the data reliably because PCC Community Wellness and Lawndale Christian Health Center submitted Objective Data sheets for a combined total of 13 clients, and only four of these clients completed indicator panels. For two of these cases, the value recorded in the Objective Data Sheet for the number of ER visits in the previous 90 days matched the value recorded for the indicator panel that reflected the same time period, for a third the values did not match though both indicated at least one ER visit, and for the fourth, the value was missing from the Objective Data sheet.

Another set of related variables that were included as a means of verifying the subjective measures with objective data were the date of last support group, group therapy session, or 12-step meeting attended versus the number of 12-step meetings or support groups attended. Calculating the time between the date the indicator panel was completed and the date of the last support group, group therapy session or 12-step meeting attended allows us to compare the objective and subjective data for the time periods that match. Of the 14 clients for whom Haymarket Center reported the number of 12-step meetings attended in the past 90 days on the objective data sheets and completed an indicator panel that covered the same time period, the data matched for 11 of the cases or 79%. Of the 19 clients for whom Vital Bridges or Genesis House reported the number of support groups or group sessions attended on the Objective Data

Sheets and completed the indicator panel for matching time periods, the data matched in 16 of the cases or 84%.

Changes Over Time

It is difficult to assess changes over time using the assessment questions or indicator panels because very few clients have completed multiple assessments with those tools. Of the 42 clients who have completed at least one set of assessment questions, only nine have completed multiple assessments. Of these nine, only two completed assessment questions more than one month apart. Of the 46 clients who have completed at least one indicator panel, only four completed multiple indicator panels. Of these four, only one client's indicator panels are separated by more than one week. Therefore, changes must be assessed using the much more limited data from the Objective Data Sheets, and demographic information encoded in the WSCC identification numbers.

Demographics

There were no significant changes in the demographics over time. While the percentage of males and females for whom objective data collection sheets were completed varied slightly (64% of those with objective data recorded in the first period were male, compared to 58% in the second period, 59% in the third period, and 60% in the fourth period), these differences were not statistically significant. There were also slight variations in average age of those for whom objective data collection sheets were completed in different periods, but these were also not statistically significant.

Objective Data

Aggregate data for Objective Data Sheet indicators appear in the table below. The text below the tables presents additional information about these indicators.

Data Collection Period		1 st	2 nd	3 rd	4 th
Dates		1/1/03-3/31/03	6/1/03-8/31/03	2/1/04-4/30/04	5/1/04-7/31/04
Visits to needle exchange in past 90 days	Cases	7	7	6	6
	Mean	3.1	2.1	1.3	1.5
Percent of appointments kept as scheduled	Cases	45	66	55	47
	Mean	93.6%	98.2%	78.2%	93.1%
Number of support groups/group sessions attended in past 90 days	Cases	31	49	49	43
	Mean	0.2	2.8	11.5	6.5
Percent positive drug tests	Cases	9	22	23	22
	Mean	33.3%	22.7%	39.1%	31.8%
Number of 12-step meetings attended in past 90 days	Cases	9	17	11	10
	Mean	17.2	19.9	15.2	23.7
Percent with lease or in supportive housing	Cases	8	16	11	9
	Mean	75.0%	100.0%	81.8%	100.0%
Number of contacts/Number of contact attempts	Cases	6	12	8	8
	Mean	1.5	1.3	0.8	0.8

During the course of the study one new HIV infection was documented in the objective data for one client, and one new Hepatitis C infection was documented in the objective data for another client. Data on sexually transmitted infections were missing for one or more data collection periods for a number of clients.

Some variation could be measured in recorded drug use among the four objective data collection periods. Only Haymarket Center and Genesis House collected objective data to document drug use; over the 19 months of data collection these two agencies submitted at least one data point on drug test results for thirty clients. Of the thirty clients, six only had data regarding drug test results recorded for one of the data collection periods. Of the remaining 24, eight had both

positive and negative results recorded for drug tests between January 2003 and July 2004. The number and percent with positive drug tests varied. In the first data collection period three clients (33%) had positive drug tests; five (23%) tested positive in the second data collection period, nine (39%) in the third data collection period, and seven (32%) tested positive in the final data collection period.

The table below shows the results of paired sample t-tests comparing the first and second data collection periods, the second and third data collection periods, and the third and fourth data collection periods for each indicator. Statistically significant mean differences appear in bold type.

	Data Collection Period	First Pair		Second Pair		Third Pair	
		First	Second	Second	Third	Third	Fourth
Visits to needle exchange in past 90 days	Cases	7	7	6	6	6	6
	Mean	3.1	2.1	2.2	1.3	1.3	1.5
	Mean Difference	-1.0		-0.8		0.2	
Percent of appointments kept as scheduled	Cases	42	42	50	50	45	45
	Mean	93.9%	103.6%	99.4%	78.1%	83.0%	95.1%
	Mean Difference	9.7%		-21.3%		12.0%	
Number of support groups/group sessions attended in past 90 days	Cases	30	30	45	45	43	43
	Mean	0.2	0.3	3.0	10.4	13.1	6.5
	Mean Difference	0.1		7.5		-6.6	
Percent positive drug tests	Cases	8	8	15	15	21	21
	Mean	37.5%	12.5%	26.7%	46.7%	38.1%	33.3%
	Mean Difference	-25.0%		20.0%		-4.8%	
Number of 12-step meetings attended in past 90 days	Cases	8	8	10	10	10	10
	Mean	15.6	21.3	21.2	14.7	16.7	23.7
	Mean Difference	5.6		-6.5		7.0	
Percent with lease or in supportive housing	Cases	6	6	9	9	9	9
	Mean	66.7%	100.0%	100.0%	77.8%	88.9%	100.0%
	Mean Difference	33.3%		-22.2%		11.1%	
Number of contacts/Number of contact attempts	Cases	6	6	8	8	8	8
	Mean	1.5	1.2	1.0	0.8	0.8	0.8
	Mean Difference	-0.3		-0.2		0.1	

Each of these paired comparisons involves only the clients with complete data for both data collection periods being compared, so they are accurate indications of the changes experienced by the individual clients for whom the agencies were collecting data at the time. The largest changes appear to have taken place for clients between the first and second data collection periods. This probably reflects the early impacts of treatment. While there were some statistically significant differences in the objective data measures among the four data collection periods, these differences do not appear to form any clear trends. Though the largest impacts seem to have taken place early in the study before the pagers were distributed, some of the differences may be attributable to the effects of the pagers. This possibility is further explored in the next section.

Correlations of changes with pager activity

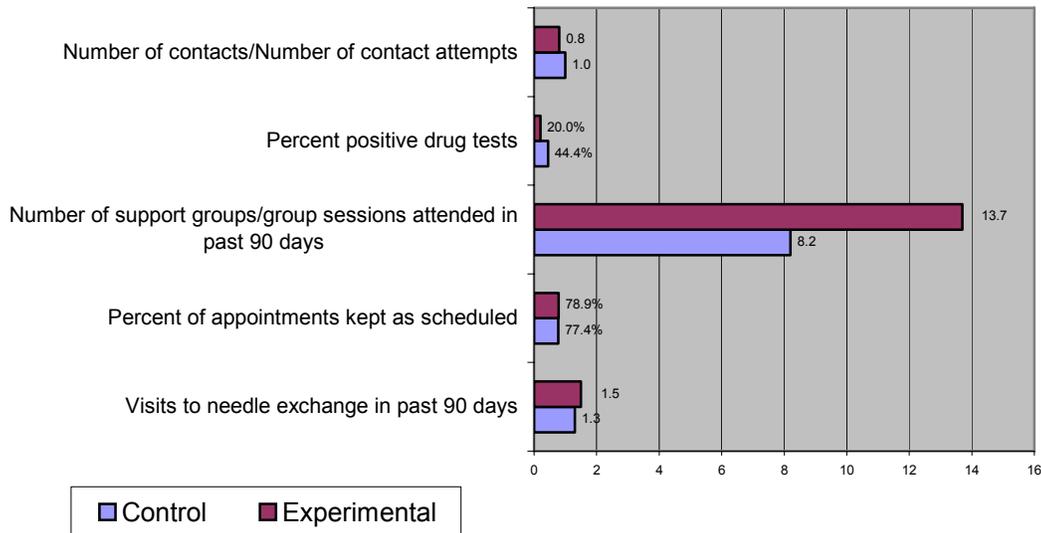
Though the paired-sample t-tests did not reveal statistically significant improvements between the second and third data collection periods in the whole population of clients, there may still be improvements in the experimental group. Independent sample t-tests were used to determine whether there were any measurable differences between the experimental and control groups, and an analysis was conducted to measure whether there was a significant relationship between the number of pages received and changes in risk behavior and compliance levels. The table below shows the results of the independent sample t-tests for the objective indicators for the four data collection periods.

	Data Collection Period	6/1/03-8/31/03			2/1/04-4/30/04		
		Cases	Mean	Sig. Diff.	Cases	Mean	Sig. Diff.
Visits to needle exchange in past 90 days	Control	5	2.2	0.92	4	1.3	0.87
	Experimental	2	2.0		2	1.5	
Percent of appointments kept as scheduled	Control	34	97.8%	0.96	24	77.4%	0.91
	Experimental	32	98.6%		31	78.9%	
Number of support groups/group sessions attended in past 90 days	Control	20	3.6	0.52	19	8.2	0.57
	Experimental	29	2.3		30	13.7	
Percent positive drug tests	Control	21	19.0%	0.06	18	44.4%	0.33
	Experimental	1	100.0%		5	20.0%	
Number of 12-step meetings attended in past 90 days	Control	17	19.9	NA	11	15.2	NA
	Experimental	0	NA		0	NA	
Percent with lease or in supportive housing	Control	16	100.0%	NA	11	81.8%	NA
	Experimental	0	NA		0	NA	
Number of contacts/Number of contact attempts	Control	5	1.7	0.21	2	1.0	0.20
	Experimental	7	0.9		6	0.8	

In the table above, “cases” refers to the number of clients for whom that data collection was completed and whether they were in the experimental or control group. “Mean” reflects the mean value for that indicator for clients in that group, and “significant difference” is the probability that the difference in the means between the experimental group and the control group is the result of chance rather than reflecting an underlying difference in the populations as a result of the intervention.

Data are presented for the second and third data collection periods to illustrate two points about the control and experimental groups. The first point is that the groups were not significantly different before the pager intervention. This was important to verify because, although clients were originally assigned randomly to either the experimental or control groups, some agencies took some liberties in reassigning pagers originally allocated to clients who had dropped out of the study to any client that would agree to take one and for whom they could reconstruct the objective data.

Comparison of Control and Experimental Groups Third Data Collection Period



The second point is that even after the pager intervention the control and experimental groups did not show statistically significant differences in the objective data indicators measured. However, the graph above illustrates that there were some small differences between the groups; these differences simply were not statistically significant at the 0.05 level.

As expected based on this preliminary analysis, there was no statically significant correlation between the number of pages received and the values reported on the objective data collection sheets.

Conclusions

Though the lack of a statistically significant, measurable impact on the objective indicators is a disappointment, it does not erase the real benefits for clients and agencies identified through the qualitative elements of the ongoing program evaluation. This is a reflection of the great difficulty of the task undertaken and the client-oriented focus of the agencies involved.

Challenges

The process evaluation reveals a number of issues inherent in such efforts that make it difficult to achieve the tasks undertaken. Fundamentally, the different agencies participating in the TOP-TBAP project have different capacities, needs and priorities, and the TOP-TBAP project represented a relatively small part of the activities of each agency. The second issue was that the level of buy-in among administration and staff at the participating agencies was inconsistent. During the course of the three-year project enthusiasm levels varied as other commitments and work were also pressing. The third issue was that it simply took longer to design, build and fully implement the technology than originally planned, and these deviations from the timeline impacted the measurable success of the project. These impacts were due to the reduced time for data collection and the fact that a number of the clients originally selected for the study dropped out. But more importantly, agencies became accustomed to using the two-way agency pagers that were introduced in the interim and which did not record the same data as the web-based system. The final issue was that the TOP-TBAP project was a pilot study that only affected a small percentage of clients at each agency. The impacts of these issues appear in the following table.

Issue	Impact
Different needs, capacities and priorities at each organization	<p>Agencies had varying levels of technology access and proficiency, and some staff needed additional training to be comfortable with the technology</p> <p>Agencies that were more involved in the planning/design phase tailored some elements to fit their needs; system not ideally configured for all agency users</p>
Inconsistent buy-in	<p>Project not always a priority. Fluctuating commitment levels lead to inconsistent participation in the project and frequent difficulties in completing data collection on schedule</p> <p>Change management a challenge because of staff reluctance to adopt and use new technology</p> <p>Staffing changes had unnecessarily large negative impacts at several agencies</p>
Technology delays	<p>Agencies substituted two-way agency pagers for web-based referral system</p> <p>Reduced time for measurable impacts and data collection</p>
Pilot project	<p>Momentum lost toward end of project</p> <p>Need to collect data left agencies frustrated that they could not choose the exact clients for experimental group</p> <p>Necessity to secure baseline data may have skewed selection</p>

Organizational Differences

Each organization came into the TOP-TBAP project with a different set of capacities, priorities, and expectations for the project, and different relationships with the lead agency. Capacities varied in terms of staff, leadership availability, and technological savvy.

While many organizations reported in the key informant interviews that upper-level management had originally been involved in the project, the job descriptions of the staff to whom the implementation of the project was delegated varied. At some agencies, the staff members who did the actual recruitment, data collection, data entry and online referrals provided other intake services. At other agencies the primary staff involved performed mostly administrative functions. Exact domains of responsibility were not always clear.

Participating agencies varied in the extent they had access to and used web-based technology before the project. As part of the project, all agencies' computers and internet access were upgraded as needed to insure that all the agencies would be able to use the shared technology. Some agencies only needed minor upgrades; others needed significant investments in hardware.

A second impact of the varying priorities of the agencies involved in the project was that the areas of emphasis of organizations that were not heavily involved in the design phase might be under-represented in the final design of the *Equicare* system. For example, the quarterly assessment questions include a number of indicators that are of interest primarily to one of the agencies that worked on the design of the system. The system does not collect all the information that a number of agencies would like to have in order to match the data collection requirements for their other clients.

Inconsistent Buy-In

While there was a significant level of buy-in from participating agencies, that level of commitment varied over the course of the project and among staff and management at the participating agencies. Two agencies that were very involved during the planning and design phase underwent radical organizational changes in the third year of the project that limited their ability to fully implement the project. At other agencies, initial buy-in at the upper management level did not completely reach the direct service staff. This was particularly true at the agency that was geographically isolated from the rest of the agencies involved in the project; their interest waned with the emphasis on referrals because they did not feel that referrals to agencies on the west side would be particularly helpful for their clients. Inconsistent buy-in led to lower than planned levels of usage of the *Equicare* system and delays in completing data collection. In addition, staffing changes at some agencies had a larger negative impact on the project than they could have with more attention paid to maintaining continuity with the project.

The lower than hoped-for usage of the *Equicare* system was not entirely unexpected. Going into the project, staff members at the lead agency were aware that change management would probably be the most challenging aspect of the project. People are generally slow to change the way they do things, particularly when it means adopting a new computer technology. In the key informant interview some staff reported that they felt the project simply added more work to their already overburdened workdays. The demand of the project were often viewed by various staff members as work that distracted them from their main task of providing direct service to clients or administering programs that directly served clients. The meetings, which were particularly frequent during the planning and design phase of the project, the multiple half-day trainings in how to use the online system, the data entry of client information into the *Equicare* system, the paperwork to enroll clients in the study, and the efforts to keep clients enrolled in the study were all time consuming. In the set of key informant interviews conducted with agency staff in 2003 and in those conducted in 2004, staff indicated that they often felt that the project added to their workloads. This was particularly true of staff with direct client care responsibilities, some of whom said that the additional requirements of the project diverted them from their regular activities.

Training was the primary tactic to combat this resistance to new technology. Introductory training was offered before the system went live to ensure that everyone who would be trained on the system had basic computer and internet skills. There were a number of mandatory training sessions to teach agency staff how to use the different modules of the system as they came on line. Additional trainings were available for new staff as well.

Despite the significant investments in training, some agency staff never seemed to completely embrace the technology. Some reported that they felt more training would be beneficial. Others said that using the system, particularly entering client information into the system, was a burden that diverted them from other client services. There was not enough buy-in from all levels of participating organizations to support the integration of the *Equicare* system into the day-to-day operations of providing services to clients. This lack of buy-in was most often manifest in low utilization of the *Equicare* system and delays in completing required data collection and reporting.

Since each agency was involved in a relatively small portion of the pilot project, only a few people at each agency received training on how to use the system and complete the data collection and paperwork necessary for the project. This created a risk to the project when there were staffing changes. In agencies with a strong commitment to the project at the management level, staffing

changes were handled in a manner that provided a significant overlap between the departure of the staff members who had been most involved in the implementation of the project and the transition of the new staff member to include the TOP-TBAP project in their job descriptions. In agencies where the commitment was not in place, staff changes caused much greater disruptions to the project. Existing staff may not have been in place to train new staff members, and knowledge of the project was lost on several occasions. New staff were not able to access the *Equicare* system because they did not have a password, and the agency did not have anyone trained with administrative rights on the system.

Not all staff transitions had large negative impacts on the project. One of the lessons learned was that the negative effects of staff turnover on technology projects such as the TOP-TBAP project could be reduced or almost eliminated through an extended transition period that allowed for adequate training of the new staff member. This situation is only possible with significant buy-in at several levels of the organization.

Technology Delays

It took longer than anticipated to implement several features of the TOP-TBAP project, including many of the features of the *Equicare* system. While several agencies were slow in completing their data reports, the majority of the deviations from the planned timeline were due to technology issues. It was an even greater challenge than anticipated to customize the software and add the capabilities for two-way paging. In fact, the data capture on the two-way paging was not completed in time to capture data to include in this analysis. However, since the overall level of data capture was lower than anticipated, and the data collected did not reveal that the pagers were significantly impacting risk behavior or compliance, this data would not have made a difference in this evaluation, though it may have been helpful for some of the clients and providers.

Beyond the delays in completing data collection, the delays in implementing the web-based system had an unforeseen impact on referrals once the system was finally deployed. In the intervening period, each agency was given a two-way text pager to facilitate referrals between the participating agencies. These pagers allowed staff to contact each other and receive near-instant feedback on requested referrals. This was particularly helpful for outreach workers, but users at other sites also reported that this was a very valuable tool. The pagers were so convenient, staff continued to use them even after the *Equicare* system was in place, bypassing the web-based system. Thus, there were very few referrals recorded in the system over the course of the project, and referrals were not analyzed in this report.

The other impact of the technology delays and inconsistent buy-in is the low number of clients enrolled in the study for whom there was complete data collected over time. Fewer clients than planned on were enrolled in the study, and fewer data were collected for each client. As discussed in the findings section of this report, there were very few clients for whom there were multiple quarterly assessments or indicator panels completed, so the only data that could be compared over time came from the objective data collection sheets. This weakened the analysis considerably. The data available are insufficient to demonstrate that the project met its goal of a 30% increase in the number of clients who successfully completed referrals.

Pilot Project

The TOP-TBAP project was a pilot project, and, as such, was never fully integrated into the daily process of serving clients at the participating agencies. The fact that the TOP-TBAP project was a test study added a challenge to maintaining momentum among the coalition members;. Additionally, the need to assign clients randomly to the experimental or control group and to collect objective data to document outcomes frustrated agency staff and may have skewed the selection of clients for the study.

Because agencies came into the project with the understanding that the project would end when funding ended, agencies became less willing to invest time and resources into the project as the

project end date approached. A clearer commitment from the lead agency to maintain the *Equicare* system after the initial pilot project may have encouraged partner agencies to make the necessary IT investments to allow their existing data systems to import common data elements from the *Equicare* system.

Agency staff expressed frustration with some of the constraints they faced because the TOP-TBAP project was a pilot study for which data had to be collected to measure the impacts of the project. They wanted to be able to provide all their clients with the pagers or to be able to select which clients would receive the pagers and which would be in the control group based on their perceptions of who they thought would benefit the most.

In addition, the necessity of securing baseline data from which to measure change may have skewed the selection process. Because many of the agencies did not have a large number of new clients who met the population criteria to enroll in the study, many of the clients who were identified for inclusion in the study were established clients. By the time the study started, these established clients had already received many of the referrals they needed, and many may have been more stable than the typical clients of the agencies in the collaborative. These factors may have reduced the measurable changes that were possible to document in this project.

Successes

Despite the challenges of the project, there were some notable successes. The technology was rolled out, and it did have positive impacts on agencies and clients. In addition, the strong links agencies developed in the course of this project constitute the foundation of an ongoing integrated system of care for the west side of Chicago.

Agency Impacts

The technology introduced to each agency and the training provided enhanced the agencies' usage of technology. Staff members with limited technological proficiency at the start of the project reported the greatest increase in comfort with technology, and several of them transferred to other positions that required their new skills with technology. A baseline survey of technology usage and the efficiency of referrals was conducted before any of the technology for the project was rolled out. A final survey was conducted at the end of the project to measure changes in technology usage.

There were statistically significant increases in the percent of respondents using email at work to communicate with other organizations regarding clients and for updates on work-related activities. All respondents to the final survey reported using email to communicate with people in their own organization and for networking, substantial increases from the 82% and 73% respectively reporting those uses for work email in the baseline survey. In addition, the percent that reported using email at work to communicate with clients more than doubled, from 18% in the baseline survey to 40% in the final survey. It is likely that this increase includes project staff using the web-based system to contact their clients by pager, since the initial focus groups with potential clients to get feedback on their technology preferences did not indicate that many in this population had access to email.

The percentage of respondents reporting that it took less than half a day to initiate and confirm a referral almost doubled from 36% in the baseline survey to 60% in the final survey. The percent reporting that it took between half a day and one day decreased by half, from 41% in the baseline survey to 20% in the final survey. No respondents reported that it took more than a week on average to initiate and confirm a referral in the final survey. These improvements almost certainly reflect the deployment of the *Equicare* system and the two-way pagers.

The percentage reporting that contacting case managers and providers at other agencies to make a referral was not at all cumbersome almost tripled, from 13% in the baseline survey to 36% in the final survey. The percent reporting that it was somewhat cumbersome decreased

from 78% in the baseline survey to 55% in the final survey. This change almost certainly reflects the implementation of the *Equicare* system and the two-way pagers.

The percent of respondents agreeing that the amount of time it takes to coordinate referrals compromised their ability to serve their clients decreased from 63% in the baseline survey to 20% in the final survey. While some of this change may reflect differences in the populations completing the baseline and final surveys, it is very likely that the improvements reflect the implementation of the *Equicare* system.

Changes in technology usage between the baseline survey and the final survey reflect both the differences in the populations completing each survey and the effects of the investments in technology and training for the TBAP project. While it is not possible to distinguish between these two factors in this analysis, it is reasonable to believe that both play a factor.

The changes in the perceived efficiency of referrals, while not statistically significant, are likely the result of the technology and training investments of the TBAP project. Another factor increasing the efficiency of referrals is that representatives from agencies participating in the project have developed stronger relationships with each other as a result of working together on the project. This makes referrals more efficient because referring agencies know whom to call, and receiving agencies may be more likely to make resources available.

Client Impacts

In addition to the small, non-statistically significant impacts on clients documented in the quantitative portion of the evaluation, clients reported on their experiences with the pagers in a focus group in May 2004. Overall, the pagers made clients feel empowered, and they reported that they helped them remember to take their medications as prescribed.

Clients have a generally positive impression of the pagers. One client in the focus group said that the pager made her feel important; she really appreciated the pager and the effort to reach out to her that the pager represented. Several participants in the focus group expressed that they have trouble organizing the daily tasks in their lives because they work, take care of children, grandchildren, or parents. The pager helps them remember to care for themselves. In addition, the pagers make it easier for agency staff to contact clients to remind them of upcoming appointments and food pantry pickup times.

Agency staff reported in the key informant interviews that, for the clients for whom the pagers were a good fit, the pagers had a large positive impact, both on concrete measures such as clients remembering to take their medication as prescribed, but also on intangible factors. One case manager said, "I was really surprised at the emotional impacts that the pager system has seemed to have, especially with clients who are not working, kind of just hanging out. It really built a lot of self-esteem and self-sufficiency in clients who were reliant on family members to remind them to take their medications. I think it was a source for some clients to realize that they are not as dependent as they thought they were. They don't need as much of the handholding that they had been receiving. After several clients had the pagers for a while they realized that they didn't have the problems keeping up with their medications and the pagers than they thought they did. With the medications becoming easier to take, the regimens have become easier, and a lot of the clients are recognizing that they do have a handle on it. Even the clients who didn't really need that type of structure have gained some confidence in themselves." The pagers empowered clients, and increased their feelings that people cared about them.

In key informant interviews with agency staff, service providers shared other successes as a result of the TOP-TBAP project. These successes included getting a pregnant woman into drug treatment and an HIV-positive patient whose CD4 count was rising as a result of the pager helping her get stabilized on her medication regimen.

Stronger Relationships

The relationships built on the shared work of the West Side Collaborative Care and the TOP-TBAP project form the foundation for an integrated system of care for the west side of Chicago. As much as the technology facilitates the sharing of information and the processing of referrals, the relationships among staff at various agencies and between staff and clients are at the heart of this project.

Relationships among staff at different agencies allow for better sharing of information on what services are available at which agencies. The closer relationships also mean that agencies receiving a referral may be more likely to make resources available to accept the referral. This is crucial for services such as drug treatment, where there are often waiting lists for services. The linkages between agencies enhance service providers' ability to meet the complex medical and psychosocial needs of their clients. With more information on available services, a greater likelihood of referrals being completed in a timely manner, and the ability to know whether the referral has been completed, service providers can better serve their clients. This more effective service may contribute to providers building stronger relationships with their clients, possibly enhancing compliance.

Recommendations

There were a number of lessons learned in this project. The most significant was the importance of securing comprehensive buy-in for the project to enhance the success of change management strategies. This project suffered because commitment to the project wavered at crucial times in recruiting clients to the study, collecting objective data to document their progress, and using the system to track their status. Future efforts should do more to secure buy-in from all levels of participating agencies.

Part of the process of securing buy-in should be to make sure all parties are clear on the expectations of the project and understand the benefits of the project. There needs to be a realistic understanding of exactly what will be required of agencies that participate in terms of time and resources.

Other lessons learned were the importance of selecting the right clients for the intervention. In this case, the clients who benefited the most from the pagers were those who were neither totally transient nor totally stable. Future interventions of this nature might target clients who are basically on the right track but need some assistance to reach full compliance.

Appendices

Qualitative Data Collection Activities

- Client Technology Focus Group Report and Documentation
- Pre-Implementation Agency Staff Key Informant Interviews Report and Documentation
- Experimental Group Client Final Focus Group Report and Documentation
- Final Agency Staff Key Informant Interviews Report and Documentation

Quantitative Data Collection Activities

- Technology Usage and Referral Efficiency Report and Documentation
- Objective Data Collection Sheets

Forms

- Informed Consent Form

TOP
Focus Groups
October 2, 2002

Background

Access Community Health Network established the West Side Collaborative Care (WSCC) in response to the identified need for an integrated, networked service delivery system on Chicago's West Side. Together they represent three community health providers, one AIDS services organization, one community-based organization and two drug treatment providers.

Two focus groups were conducted on October 2, 2002 to collect qualitative data from potential technology end users (case management clients) served by partners of the WSCC. Partners wanted to understand client's perspectives about communications, appointments, medications, preferences about the technology options, and any concerns about confidentiality.

Staff members of WSCC recruited participants from among their clients currently receiving services, and staff from Genesis House and Lawndale Christian Health Center facilitated the discussions held at their respective organizations. Abe Miller from Access Community Health demonstrated the technology options that participants were asked to evaluate. Participants were recruited from the case management clients at all either of the WSCC partners, and they received \$25 in consideration of their time.

The qualitative findings from the two focus groups are summarized in this report. Some participant's statements (in italics) have been abridged or edited for clarity.

Participant Characteristics – see Questionnaire

Communication:

Focus group participants' experiences communicating with their case managers varied widely. Not knowing when their case manager is available was a problem too.

I don't take time out to really give myself to my case manager to share information with her because of my history. It's up to me to find her.

I'm not in one place so it's hard to make a lot of time to share information with my case manager.

It's hard because some case managers work at different sites some days.

I'm getting lost in the middle because I'm just HIV. I need help I can't get help from one agency because I was there two years ago

I get mixed information, and it's very frustrating. I feel like my case manager isn't doing his job. It may be racial I've heard other people say this about this particular agency and it other people have said that African Americans don't get the services they need.

I either don't qualify or I get mixed messages. I know other people who have my status who are getting the services. Other people say I should be getting these services. He'll say he'll call me back, but I have to track him down. I've made some complaints and it seems like he's trying harder now. I'm frustrated. I ask what can I do

I'm on probation. I have a probation officer. I don't have a problem contacting her. I've been blessed...

Up until now, Well, now it's difficult because I'm at different address. When I moved, I made sure he got the new address. I stopped trying to access services because I wasn't qualifying for anything and I was working full time. It would now be difficult for my case manager to find me.

My case manger is a gift from god. Gets right back in touch with me. Fifth year being clean. Everyone needs to build a relationship with your case manager. Let them know I really need you and you can direct me to avenues that you can go to. My case manager is trying to get me housing. I'm not homeless. He does home visits.

Earlier this year I got shot, my case manager called the hospital. My case manager always knows how to get in touch.

What exactly is a case manger? Jill is your case manager. Oh, she's my case manager. I've learned something today. That's my girl. She's cool. Whether I like it or not, she tells me how it is. I'm not hard to get a hold of. I just count on you to come in everyday. I drop in every day. My case manager is more like a big sister. The sister I never had

With a telephone not being affordable, rent, food, other necessities, my stepdaughter is so busy getting calls from all the other places. I hear it from her "I'm not your message service. It's hard to depend on other people. I don't like them looking at me like I'm sick or a victim. I know it's out of concern, but i could do without them asking all the time how I'm doing. I'm grateful, but I don't like everything having to go through them. Just hearing his voice sometimes helps me out a lot.

The only time my case manager has a hard time getting hold of me is when I'm bouncing around between apartments. She has my father's number, and I talk to him every night. I also keep my appointment every two weeks. I try to

They should leave a message on their voice mail when they are not available and who you should see.

Appointments:

Participants talked about their frustrations keeping appointments that took many hours out of their day. They talked about forgetting appointments, being upset about missing appointments, and about the challenges of transportation, and lack of funds as factors that impede their keeping appointments.

Communications with the physician were good. The nurse would keep in contact if appointments would change.

I haven't been doing to well lately with my health care provider. Every six months at The Core Center they constantly change my doctors as soon as I get comfortable. Sometimes I feel medically that the new doctor not knowing me well doesn't know what the situation is. Lately I haven't really been keeping my appointments because the constant changing of doctors is irritating.

I put it on the calendar but it doesn't help.

I get upset when I miss an appointment. I have lots of problems to take care of.

If I have to stop by the core center, I have to be there all day. Sometimes I just need to know my updated copy of my viral lode every three months. If I have to come there, is there a faster way for them to provide the service I need?

When you find out that you need certain things, they need a way to be able to schedule those together.

I was bad at appointments. Jill is also my case manager but I'm bad at keeping appointments with her, because I'm in and out of detox. I haven't been able to take time to meet with my case manager to find out about free health care.

Medication:

When participants talked about their medications they explained remembering to take was only one of several issues. Some are challenged by the side effects or needing to eat food at the time they take medication, others by their decision to not disclose their HIV status, or being overwhelmed.

With the cyclovir I have to eat something to take it on a full stomach. Where I'm living, it's hard to know the menu. I've been taking the afternoon and evening. It's just too strong. It's constantly making me sleepy. The sestina is difficult taking it at bedtime and then having to get up to function. Taking it during the day is just out of the question.

The medicine itself is difficult to handle. Especially if you're working I need to get back to my regimen that I once had, because I do know that the medicine is effective. Three months ago my viral load was undetectable. You do get this sick feeling, but you have to take it. Once you start not taking it you can get in the habit of just not taking it is not safe to do that. Once you build up the immune system you have to take them. Sometimes I forget. I recently just told my family the situation. I kept a secret for sixteen years. Nobody knows. I don't set medications out. I don't let them send them to my house. I have a tendency to put them in a drawer and forget. You have a tendency to forget. With everything that's going on you do forget.

I don't take medications right now. My friend, she's goes through a lot of aches and pains with her medication. I watch her sometimes, you know have to take it, but when she's not feeling well, she doesn't want to take them. I just wish anyone well who has to take the medicines.

For me when I did have medicine, being in and out of detox. Was a problem to get the medicine? If they did provide the medicine, I didn't want to take the medicine instead of me going through withdrawal. I would just blame it on the medicine and go back to using. When I'm using I don't take my medicine, antidepressant or anything.

In one day you do lots of running around, and you will forget. I have to take my meds morning, afternoon and night. I can't remember if I've taken it so I don't want to take it cause I don't want to overdose

Sometimes I take my meds at 8 AM by the book but I work sometimes so I forget to take my meds until late at night.

Technology:

Both groups viewed demonstrations of technical devices (pager and a reminder watch) that could help them to comply with treatments modes. They talked about the communication devices they currently used and gave opinions about which devices would work for them. The indicated that confidentiality and not being able to sell the technology for drugs would be important factors for successfully using any technical device. Some expressed a preference for a telephone, because being able to talk with the case manager important. Others felt that the pager would fit best with their lifestyle, and talked about the available features.

I like the pin number.

It's not a perfect world, not everyone has told his or her partner. I would feel better with a pin.

I disagree about the pin.

I would want a pin number.

I wouldn't have this if it didn't have a pin number it's confidential.

It wouldn't bother me to not have a pin if it was someone I trusted.

I prefer the specific name of the case manager.

I like the call back.

Add a choice: You need to make an appointment, press four to reach a scheduling operator.

I actually owe for an old phone bill, so I wouldn't get a phone. I'd rather have the phone thing so I could talk to my case manager. I need something with a phone.

If I'm thinking about me being out on the street. I'm at more risk than they are. I need a way to get in touch with people.

With the beeper, you could receive messages without them having to track you down to a certain phone number

That beeper, that would be annoying

How often would the system call back until it reached you? If it called twice a day that would probably be best

Being that I, my record is checkered by past addiction, I've had a phone, but I don't keep it very long. Wouldn't the beeper be more logical for someone who doesn't have consistent phone service? I could get messages and still communicate back to them.

The system could call both things - the phone number is has and the beeper. When you get another phone, you can have your case manager put that in the system.

One of the things we're looking into is an 800 number. The voicemail really sounds great The flexibility to be reached

That's what I was about to say. If you don't have a phone number. If you leave another phone number for the case manager, if I'm not there, I'm still going to miss your message. The beeper thing is a really good idea.

I wouldn't have to worry about not having access to a phone. With the pager that message will always get to me without having to worry about finding a phone. The way I see it that eliminates any loopholes in not being able to communicate with your case manger.

I think that's a very good thing for me. You don't have to go to the pay phone and leave another number with the case manager and then having to find money to call that number and find out if my case manager has called that number. For me to be able to reply back, rather than leaving a number where I'm not stable at.

Having the pager, sometimes you need to talk to them anyway. Sometimes the fact is that you can't attend because you don't have transportation with the pager if you have to call, you can still call. With the phone, if you miss the message, you miss the message.

*What other than that would be beneficial to receive on your pager?
Medicine refills, appointment reminders. Waiting lists, doctor's appointments*

I would want to carry mine. Every number that comes through the pager is through your case manager. When you come down, you're going to want to hear from your case manager.

If I sold this pager to Jill, she would have the pager, but she wouldn't know the number.

I don't know how many pagers/cell phones for bags of rock. You can't sell it. You're got getting anything for it; you don't know the number.

*I can't send messages back on the watch. I can only receive messages.
Is that really a case managers' responsibility to remind you to take your medication.*

Part of this program is to help clients help their compliance. Normally, it's not the job of the case manager to reminder you to take your medicines.

I couldn't see putting another burden on my case manager.

I like the beeper idea because you can respond. It's hard to find a pay phone that works

I always used to sell watches. It's a nice looking watch.

If I was to relapse, the watch would go a lot faster than the pager.

The thing about the watch, being an addict, I would have difficulty not selling. Have people who had been in recovery to make sure that they've been in recovery at least a year before they could get a watch. If you're going to relapse the watch would be a lot easier to get rid of for drugs. There's no doubt that you could get something for that watch.

The watch is neat, but I'm not stable enough to trust myself with something like that.

I would feel more comfortable accessing my case manager more regularly.

If you had an 800 number in a reply to track the case manager down.

The watch would see on the street for \$25 or pawn for \$15.

The pager definitely could not be sold on the street.

The watch would be dangerous for people in recovery or doing harm reduction. The watch is still good for some people, but not for people in recovery. The fix will come first.

Conclusions

Confidentiality is a very important factor when receiving information, regardless of what friends and family members know or do not know of their diagnosis.

The resale value of any type of technology that clients receive should be carefully factored into dispensing it. The watches pose a temptation for quick selling, but pagers do not be quickly sold.

For most of the participants the challenges of daily activities are significantly complicated because of their health care needs. Both groups indicated that using technology to receive messages from their case manager would help them take their medications correctly and keep appointments.

TOP-TBAP Client Focus Group
Wednesday October 2, 2002 (11:30 a.m. – 1:00 p.m.)
Wednesday October 2, 2002 (5:30 p.m. – 7:00 p.m.)

Facilitators Discussion Guide:

Introductions

Note taker and Confidentiality: Interested in your opinions and ideas not your identity so recorder is just writing down notes so we remember what the group talked about.

Communication:

We need feedback on how easily it is for a client to contact their case manager or provider and vice versa. We also need to understand the barriers to client – case manager/provider communication and if they have some creative ideas.

Possible questions (asked opened whenever possible):

- Do you find it hard or easy to get in touch with your manager?
- When would you call or stop by to see your case manager
- What are the things that stop you from getting in touch with your case manager
- Other than appointment times, how do you get in touch with your case manager?
- How does your case manager get in touch with you?
- How do important people in your life that you do not live with (family/friends/business associates) usually get in touch with you?

Appointments:

We need feedback on how clients make appointments and the barriers they encounter to keeping their appointments. If clients miss appointments, is it because they forget and what would help remind them.

Possible Questions:

- How/when do you make appointments with your case manager or provider
- What percentage of the time do you keep your appointments
- What are the reasons for missing your appointments
- How often do you miss appointments because you just forget about it
- What would be the best way to remind you of your appointments
- Describe for me the best way for your case manager or provider to remind you of your appointment

Medication:

For those clients that miss taking their medications, we need feedback on why clients miss it and what are the barriers to taking their medication regularly. What can we do to help them take their medication consistently

Possible Questions:

- Do any of you have important prescription medicines that should be taken on a regular basis?
- How many of you are able to take your medication consistently?
- What are some of the reasons why you don't take your medication?
- Would you want to be reminded to take your medication?
- (If a reason is because you forget) what would help you remember?
- Describe the best way your case manager or provider could remind you to take your medication?

Technology:

We need to understand what communication devices they currently use and which ones work for them. Are there any barriers to getting or using this technology.

Possible Questions:

- How many of you have cell phones?
- How many of you have home phones?
- How many of you have pagers (are they text or number only)?
- How many of you have voicemail or an answering machine?

Note – consistently having these options available may be an issue for some people

Demonstration:

We will demonstrate the phone and pager technology.

We would need to understand:

- what would keep their anonymity. (???)
- likelihood of them using pagers over a phone or vice versa
- their preference for one type of pager over another
- (do they think it is easy to respond using a pager)
- their feelings about getting messages on their cell phone or their pager.

Confidentiality:

We need to know what information can be said in a voicemail (reminders, and what else)

What information should be left out of the message>

What about information sent on a pager and does it make sense to have an access code to retrieve the message?

Note – totals less than 13 indicate that some participants did not answer the item.

**1. What is your race/national origin:
(Please Circle One)**

- American (Native) Indian
- Asian/Pacific Islander
- 9 Black, African American
- 2 Hispanic/Latino
- White
- Other: SPECIFY _____

2. What is your age? R = 34-53, Mean = 42.5, Median = 41

3. What is your gender?

- 9 Male
- 4 Female

4. What is your employment status?

- Employed Part Time
- Employed Full Time
- 2 Employed Seasonally
- 9 Unemployed
- 2 Other: SPECIFY (SSI, SSDI)

5. Do you have a permanent address?

- 10 Yes
- 3 No

6. How long have you lived at your current address? Range = 1-3 (Years)

7. What is your zip code?

8. How many people live in your household?

Range = 1-5

9. Please choose the risk situations that apply or have applied to you: (Mark all that apply)

YES	NO	
7	4	Unprotected Heterosexual Sex
2	9	Unprotected Gay/Lesbian Sex
2	9	IDU (Injection Drug Use)
3	8	Homeless/Transient
2	9	Non-Injection Drug Use (cocaine, crack, etc)
4	7	Sex Exchanged for Goods (food, money, etc)

10. Do you have a phone at your current address?

- 5 Yes
- 7 No

11. Do you have an answering machine at your current address?

- 3 Yes
- 9 No

12. Do you own a cell phone?

- 2 Yes
- 11 No

13. Do you own a pager?

- Yes
- 13 No

14. Do you have Internet e-mail (AOL, Yahoo)?

- 2 Yes
- 11 No

15. What is the best way for a case manager or service provider to get a hold of you?

- Home Phone
- Cell Phone
- 3 Pager
- 8 Neighbor
- Friend
- Other (SPECIFY) _____

Pre-Implementation Agency Staff Key Informant Interviews Documenting Internal Impacts of WSCC-TOPS on Partner Agencies

INTRODUCTION

To document the internal impacts of participating in the WSCC TOPS project, MCIC developed a list of key questions that would elicit information on the effects of the project's implementation. Angelique Johnson of ACCESS Community Health Network approved the discussion guide, and MCIC conducted interviews in person or by telephone with staff from each partner agency.

When the interviews were scheduled, the contact person at each agency was asked to involve the staff at their agency that had been most impacted or involved in the implementation of the WSCC-TOPS project. MCIC spoke with single representatives from two agencies, two representatives from three agencies, and three representatives at three agencies.

Quotes from these interviews, edited for clarity, appear in italics in this report.

FINDINGS

General Involvement

Interviewees reported involvement in the TOPS program ranging from having been trained on the technology or collecting data for reports to attending weekly working group meetings. Several specified that they provided feedback on what should be in the database forms or *“what they should be looking for in terms of referrals. For substance abuse, primary care, homeless shelters, things we know our clients need here.”*

About half the interviewees differentiated between TOPS and the West Side Collaborative of Care, responding to the question about their involvement with TOPS with activities clearly pertaining to TOPS, such as participating in the TOPS working groups, providing information about Equicare, or compiling data about clients to be included in the system. Others less clearly distinguished between TOPS and the work of the collaborative as a whole, noting, for example, *“I’ve been in on the process since the very beginning.”*

Involvement in the WSCC was variously described as “attending monthly meetings” or as attending trainings, talking with other members, or working on community involvement and making referrals and connections needed by clients in the community.

Participation in Monthly Meeting

Most of the interviewees have been involved with the collaborative either since early in the project or since they started with their organization. Several reported taking over the responsibility for attending the meetings from their Chief Operating Officer, Executive Director, or other senior administrator. A few agencies reported that several people had regularly attended meetings over the course of the project.

There was a clear divide between those who understood the purpose of the project immediately and those for whom the project did not really make sense until they had been involved for several months to a year. Several mentioned that things really became clear once they saw the software and how it would work.

Organizational Support

While some of the participating agencies target areas or populations beyond the Westside, most of the people interviewed view WSCC-TOPS project as supporting their organizations' missions.

- *Absolutely. By all of them being a part of us we are like sisters and brothers in kind and it helps with the referrals.*

I think our priority is to meet our mission, to provide services to people impacted by HIV and help them become as self sufficient as possible. Prevention becomes one of our priorities because that is one way to stem the tide. We see this project as furthering that priority.

- *I wouldn't go so far as to say that the actual project isn't the priority as much as the services and the connections that are our mission.*
- *Priority? - I make the meetings. I participate. Would we go under without it? No.*

The few agencies that seemed less enthusiastic in identifying the project with their organizational mission noted either that they provide very specific services for a specific population in a manner that does not facilitate referrals among the collaborating agencies or that the complexity of the project limited their ability to implement it.

They know that WSCC and TOPS are priorities for their organizations because they have the support of their administration to dedicate time and resources to the project.

- *Special priority for us are people with HIV, people mandated by courts and pregnant women. We've added WSCC at risk population as a priority. It's evidenced by if we have a referral coming in that person gets an immediate admit. If one of the WSCC clients is on a unit and has no funding, the WSCC clients are maintained even they have no funding.*
- *It's a priority from the standpoint that my COO wants us to participate.*

The West Side Collaborative of Care and the TOPS project have generally high levels of support from the participating agencies. Representatives who attend the meetings share necessary information with their teams who provide client services and outreach and inform management of ongoing activities and resource needs.

Impacts

Participating agencies have dedicated significant time and resources to the WSCC-TOPS project. For the most part, however, they consider it part of their regular activities. This

is particularly true of agency representatives with primarily administrative responsibilities:

- *Not much. Somewhat. That's a hard question to ask. Being in an administrative position, you're always busy. I don't start my workday until after five because I'm in so many meetings. I don't think that's just west side collaborative. It's all the meetings. They add up. Your day is consumed with all meetings and you can't get your work done.*
- *I don't think it has diverted from our regular activities because it supports our activities. Even before the system, the pagers made it easier to make referrals in a quick manner.*
- *My time would be the same, just a little less chaotic.*
- *Possibly different meetings, paper work, spending more time trying to get clients into services, being on the phone making millions of phone calls.*

Some interviewees with more direct client contact noted that the time spent on WSCC-TOPS did divert them somewhat from providing services to clients.

- *It has. I've had to cancel coinciding meetings or not attend the meetings that I've wanted to. It diverts my attention from other projects, but so do they.*
- *There's a meeting every week. There's a lot I could be doing internally in terms of encounters with clients. Meetings go on and on and we just don't get anything done. We've finally gotten to the pagers, which is what we signed on for originally.*
- *There were times when we had to do the big crunching of referrals; that took a lot of time to get that caught up. That took them away from their day to day work.*
- *I would be spending quality time with clients.*

The majority of agencies report making more referrals, particularly to Haymarket, but the number of referrals they receive has not increased dramatically. Even before the TOPS system came online, the increased knowledge of the services other agencies provide and who to call at each agency facilitated referrals. The main reason cited by respondents for why the number of referrals to their agency had not increased substantially was the strict criteria their clients had to meet before they qualified for services. In addition, before the TOPS system came online, it was difficult for agencies with open admissions policies to know whether a new client was a referral if the client did not present a paper referral form.

- *Slightly. The referrals are stagnant because we have five slots that are designated. The referrals that have increased because of our knowledge of the other organizations and what they each can do.*
- *We haven't been getting referrals because all our clients have to be HIV+. They need to have HIV to get case management. We can't right away put them in case management unless they come through certain channels. If they want to come in for pantry and food services or housing services, we can do that.*
- *We've had referrals from agencies that have never referred to us. Like family guidance will walk people over where they never had done that in the past.*
- *One of the agencies is in Oak Park and didn't know anything about us. Now they can make referrals to us.*

Interviewees noted that although the numbers of referrals may not have increased dramatically, the ease and effectiveness of the referrals process has improved dramatically. That has improved their ability to provide clients with the services they need.

- *They may not have increased, but it is more effective. It is a successful referral. We were able to cut through the red tape. Making referrals as well as getting them.*
- *It makes it easier to get follow-up or additional services for patients.*
- *Within our monthly reports it gives us more successful referrals. Instead of just sending them and not knowing what happened.*

Participants value the training and resources they have been able to access through their participation in the WSCC-TOPS program. The technology training has had widespread impact as agency staff learn the Equicare system and the prerequisite computer and internet skills. Training sessions and meetings have helped agencies improve the services they can offer clients.

- *The computer training has been the essential training at this point, and that's been great. We were one of the agencies that was current. We got software upgrades but no new hardware.*
- *The navigating the internet 101 thing and the two trainings that Abe gave on the equicare product.*
- *Those meetings were very beneficial. I got a chance to meet people who work with CDC and how they view the process and what they're looking for from the collaborative. I have a better understanding.*

- *I've been to the five trainings. Prevention case management training, six trainings since I've been in this project. Testing and counseling. I got certificates for them. The TOPS program had a training on the database system.*
- *From the case management point of view it's enhanced it quite a bit. Educating on what services are needed, how to get them and who to talk to. It's enhanced my skills in terms of the case management. I'll know exactly what I need to do.*

Expectations

The Equicare system was being rolled out at the same time as these interviews were taking place. Respondents reported that they were just getting started on the system, or that they weren't using it much yet but intended to.

- *Mainly it's information gathering when we get referrals. We'll also use it for sending referrals.*
- *We were going to roll it out by accepting referrals. We're not focusing much further than that. I don't know if any of our clients will be eligible for the technology.*
- *We're using it. It's a process. We've started but we're not adding clients everyday like we should be.*

At two of the agencies the system is already replacing paper referrals to the other agencies in the WSCC.

- *It's replacing the paper form for our referral service. That's inadequate - it's a triplicate form. In theory the third copy gets mailed back, but it's a very faulty system. We expect this to replace that as well as the current quarterly reports that we do.*
- *We don't need to make the paper referral. The great thing about it is once I make the electronic referral it pages that person. I don't need to get on the phone and call to let them know what's going on. They'll know automatically.*

However, the Equicare system cannot replace all forms, and a number of agencies discussed the need to maintain multiple systems to comply with the requirements of their various funders.

- *We have an internal database for tracking clients. It would be helpful to us in terms of tracking the work we do with tops clients. Since the systems are not integrated, we continue to track the clients because those clients are receiving other services that are not being tracked by tops.*
- *No. Keeping the paper system and adding the computer system. We can't get rid of the paper system because of funding.*
- *No. It doesn't interface with our electronic system*

Despite the limitations that make some agencies view the Equicare system as an additional burden, they are all very clear on the benefits they expect from the system. Their expectations seem realistic, and the interviewees seem excited about the coming phases of the TOPS project.

- *Expediting client services, client not waiting long for intake or services. Tracking will be great too.*
- *I'd like to see that our clients have been made a referral and that it's gone full circle.*
- *Hopefully a couple of pagers for clients. That goes back to the initial reason we signed up for it, the adherence counseling to get patients to adhere to their medications.*
- *Ease of making referrals. It'll be easier for patients because they won't have to do as many intakes. Better services overall. Reminders about meds and appointments scheduled doctor visits and things.*
- *Easier referrals, easier tracking*
- *Short term: the same theory that TOPS is looking for is what we're looking for; that if we use technology to help clients, does it help clients with compliance to keep their appointments, and does that improve their health. Long term, it answers how we can integrate that model into our programs.*
- *I think it's going to make making multiple referrals a lot easier, helping someone to get hooked up in several different ways, track where they've been all on one document and see where they need to go. To keep track of our clients and see how they are doing, and I hope it helps clients to adhere more once we get the pagers working.*

While most of the agency representatives report that they are comfortable with the idea of using the TBAP system with clients not enrolled in the study, fewer think that their agency will greatly expand the use of the system.

- *Not at this point. We're open to the idea, but we would have to figure out a way to make it less time consuming for the health support workers who are entering data. The only way we could do that would be to have just a selected number of people entered into the system.*
- *We would consider it. Eventually, I think that's where it's all going to lead anyway. The clients that use our paper system, they're all enrolled in programs here. We expect TBAP to replace the paper system. There would be a lot of work getting all our previous clients into the system*

- *We have not done that, it's something that we would have to think about.*

The main hurdles to overcome in realizing these visions are not the technical glitches that slowed the roll-out of the Equicare system at some of the agencies. Rather, the biggest issue will be managing agencies' reluctance to change.

- *The one thing is there's always the change management issue in any technology roll out. User buy-in and management buy-in. Training and overall use of the product. The benchmarks are that one third accept the change, one third don't and one third is on the fence. That has been a challenge. We're looking to implement the pager system for the client, which is going to incorporate more, and would really give these agencies an incentive to really use the system. I do know when we first rolled this out that we could add more training to get more comfortable with the software and some mandates on how to use the software.*

CONCLUSION

Final comments from interviewees were positive and optimistic. The work accomplished to date, whether measured by the strengthened relationships between participating agencies, the cooperative development and deployment of the Equicare system, the design of the adherence module or the knowledge and skills gained by project participants, gives every reason to be pleased. While some of the agencies are more involved or invested than others, the TOPS project has been successful in keeping participating agencies engaged in the process. This will be key in securing the benefits of the project for participating agencies, their clients, and the community.

Documenting Internal Impacts of WSCC-TBAP on Partner Agencies Conference Call Discussion Outline

Preliminary

- Taping Conversation
- Introductions – Names and Titles of participants

General Involvement

- What has your role been in the development and implementation of the TBAP system?
- What has your role been in the development and implementation of the WSCC?

Participation in monthly meetings

- Who started coming initially?
- At what point did you understand the purpose of the project?
- Distribution of information/updates from monthly meetings – how? Who?

Organizational Support

- What are your organization's priorities? Is TBAP/WSCC a priority for your organization? How do you know whether TBAP and the WSCC are priorities for your organization?
- How does your organization support the work of WSCC?

Organizational Impact – Time, Referrals, Resources/Training

- Has your involvement in TBAP/WSCC diverted you from your regular activities?
 - If you weren't involved in TBAP/WSCC, what would you be doing with the time you spend on TBAP/WSCC?
 - Has anyone been hired specifically to work on TBAP or WSCC-related activities?
- Has the number of referrals you make and accept increased? How has that affected your organization?
- What resources or training have you been able to access as a result of your organization's participation in the WSCC TBAP project? How has that affected your organization's ability to carry out its mission?

Future

- How are you rolling out the TBAP system internally? Is it replacing any paper forms you currently use?
- Were/are there any hurdles to overcome?
- What do you see coming out of the TBAP system? What do you want to come out of it?
- How comfortable are you with the idea of using the TBAP system with clients not enrolled in the study? Is that something your agency is considering?
- Is there anything else you want to say about the project?

Access Community Health Network Technology Based Adherence Project
End User Feedback
Focus Group Discussion with Clients
May 18, 2004

Background

Access Community Health Network established the West Side Collaborative Care (WSCC) in response to the identified need for an integrated, networked service delivery system on Chicago's West Side. The collaborative represents three community health providers, one AIDS services organization, one community-based organization and two drug treatment providers.

The WSCC Technology Opportunity Program - Technology Based Adherence Project (TOP-TBAP), funded through the U.S. Department of Commerce, is a project to use web-based and wireless technology to facilitate referrals and information sharing among participating collaborative agencies and increase client adherence to treatment plans. TOP-TBAP is expected to impact both the clients enrolled in the technology study and the collaborative agencies developing and using the technology. Ongoing data collection using the web-based *Equicare* system and agency records is one element used to assess the impacts of the project. The other element is focus groups or conversations with clients and agency staff.

In October 2002 focus groups were conducted with potential end users. They suggested that pagers would be the preferred technology for improving adherence to treatment plans. The WSCC and TOP-TBAP project team worked to implement a web-based client referral and tracking system that incorporated two-way text messaging to client pagers.

Methodology

Starting in late February or early March 2004, clients randomly selected for the experimental group received pagers. Case managers taught clients how to use the pagers and programmed relevant reminders into the *Equicare* system to page clients for appointments, events, medication reminders and other activities relating to their care plan.

To assess clients' experiences with the pagers and with the Technology Based Adherence Program (TBAP), the team scheduled focus groups in two locations and asked participating agencies to assist in recruiting eligible clients for the groups. Focus group participants were given \$25 stipends.

The goal was to recruit ten to twelve participants for each group, one of which was scheduled to take place in the afternoon at Access Community Health Center on Madison and the other in the evening at Vital Bridges in Oak Park. PCC Community Health Center and Lawndale Community Health Center each recruited one participant for the focus group scheduled at the Access Madison Family Health Center. Vital Bridges recruited sixteen clients for the group scheduled at their site. Due to the small number of participants recruited for the Access Madison Family Health Center group, that group was cancelled, and those participants were invited to attend the group at Vital Bridges.

Demographics

A total of five participants attended the focus group, perhaps due in part to inclement weather the day of the focus group. All participants were African American. There were two males and three females in the group. One respondent reported being employed part time; another was employed seasonally, and one indicated he was unemployed. Two indicated they received SSI.

Four of the five participants reported having a permanent address. Time at their current address ranged from two months to 25 years, with a median of 3 years. Household size ranged from one to eleven, with a median of four.

Three participants indicated that unprotected heterosexual sex was a risk situation that applied to them at some point; one more indicated use of non-injection drugs as a risk factor. One did not indicate any risk situations that applied to him.

Three participants had been using their pagers for at least several weeks. One participant had just received her pager that day, and another, the partner of a participant, had not received a pager and was not a member of the experimental group. He was invited to stay in the group to share his perceptions and to maintain the goodwill of the group, some of whom knew each other from other agency activities.

Participants represented a range of frequencies of being paged. One reported being paged a few times per month, another a few times per week, another every day and a fourth more than once a day. They are paged for case management appointments, doctor appointments, special events, and medication reminders.

Discussion

A trained focus group moderator, Melissa Kraus Schwarz, lead the discussion. Ms. Schwarz is the project evaluator from MCIC (Metro Chicago Information Center) hired by Access Community Health Network, and she is familiar with the program goals and the challenges encountered in implementation of the project.

Participants were guided in the discussion to share their experiences in a comfortable setting. The discussion started with warm-up questions designed to get people talking. Participants introduced themselves and said whether they had ever had a pager before they got one for the TBAP project. Three had never had a pager before, and one had a pager in the past but reported that the study pager was the only one she had currently.

Project Implementation

The focus group discussion was intended to understand the project from the clients' perspective, particularly the impacts of delays in the timeline, how well agency staff conveyed the purpose of the project and answered their questions about the project, and how clients felt about using the pagers. Client comments, edited for clarity, appear in italics in this report.

Impact of Timeline Delays

Anecdotal evidence from case managers participating in the TBAP program suggested two opposing impacts on client participation due to the delays in implementing the adherence (pager) module of the project. While some reported great difficulty in maintaining contact with and the interest of clients originally designated as part of the

experimental group, others reported that their clients were eagerly awaiting the distribution of project pagers. Given that the majority of clients recruited for the focus group did not attend, it is likely that those who did attend represent the most organized, compliant or involved of the populations targeted for this project.

Most participants reported that they were told last year about the project by Manuel (prevention specialist who was heavily involved in implementing the project at agency hosting the focus group). Most were anxious to receive their project pager. Several reported frequently checking on the status of when they would get their pager, others did not follow up.

- *Manuel told me that he was going to put me in the program and get a pager. To get feedback. Then he left and I never got one until last week. That was last year [that he told me].*
- *I've had mine a couple of months. Like [another participant] Manuel told me I was getting it. I got it in April this year.*
- *Late October, early November he told me to keep checking back. He said as soon as they come in I'd get the first one. They were looking for eligible people.*

There was a significant time lag between when participants learned about the project and the possibility that they would receive a pager and when they actually received their pagers. Two participants received their pagers in March, one in April, and one immediately before the focus group in May.

Clients' Understanding of Project

Focus group participants had varying ideas about the purpose of the project. Most understood that the project would help with communications and remembering medications and appointments.

- *It would help keep us going and give us an extra boost. When I came back Manuel was gone. He told me he was leaving. So far, I've been here since '95 and you put up with my message and I appreciate it. I gotta keep going with all your love and reaching out. You all get on my butt, but I thank you.*
- *[I was was told I was a] good candidate for the program and would be getting a pager.*
- *[There would be] group sessions once in awhile.*
- *It's a reminder.*
- *I believe it was designed in extreme cases to communicate. One purpose is to be reminded for appointments or meds...and no, you can't have your homeys page you.*

All four participants who had pagers remembered signing the consent form. They felt the form was clear, and they did not have any concerns about receiving pagers for the project. In this regard the focus group participants may differ from other study participants. Collaborative project staff reported that a few clients declined to participate in the study due to concerns about confidentiality or reluctance to come in to the agency more frequently for additional services.

Instruction on Pager Usage

Participants said that they got some instruction in how to use the pager, but several said that they did not really learn how to use the pager until they had the opportunity to play with it for a while. Some still had questions on how to use various features.

- *When I was first introduced it was not explained well. A lady came to my home and I couldn't get it. The session went so fast. The trainer was not at this location and couldn't help me.*
- *Complicated*
- *If you play with it, it has a group of replies like "Are you out of your meds?" "Did you take your meds?"*
- *Complicated – do I want to delete this? Constant reminder for a few days out of a week that's enough.*
- *I answered "no" to see what it would do. I'm still waiting [for a reply].*

Overall, the sense was that most of the focus group participants had figured out how to use the basic features of the pager, but some did not feel completely comfortable with the technology. However, the clients who attended the group may be among the higher-functioning clients served by this project; many clients may need additional encouragement and demonstrations of the technology to feel comfortable with the pagers and to use the pagers effectively.

Project Impacts

The second part of the focus group was intended to understand how the pagers impacted clients and their adherence to their treatment plan. They were asked how they feel about their pagers, and most of their comments were neutral or positive. (Suggestions on how to improve the project appear in the next section.)

- *Personally, it makes me look important. When I got it I went to my mother's house in the suburbs. I fell asleep on the couch and it went off. My mother said "What do you need a pager for?" I'm somebody, and I feel like the pager shows that people care about me. It does remind me because I take my meds hours before I go to bed.*

Participants were then asked how they use their pagers and how often they get paged. Some of the participants reported that they always carried their pagers with them because they thought they might otherwise miss messages or forget things for which they wanted reminders. Others reported that they sometimes forgot to wear their pagers or decided not to carry them.

- *Yes, because I'm busy watching TV or reading and you can forget for a whole day. It's easy [to forget].*

Reminder Frequencies

Participants reported a range of reminder page frequencies from a few days a week to twice a day. Those who were on medications received daily pages reminding them to take their medications as scheduled. All were satisfied with the frequency of reminder pages and felt that they did not want or need to be paged more frequently. Some expressed concern that asking for additional reminders would overly tax their case manager or that it was not their case manager's job to remind them of everything.

- *Three to four times a week.*

- *Twice a day*
- *How often it varies.*
- *Twice a day, seven days a week. Right amount.*
- *Constant reminder for a few days out of a week that's enough.*
- *Everyone has different needs. It could use enhancements and it would make it better for all concerned. Use it to its fullest potential.*
- *I get paged for food pantry, appointments, meds. I have over 200 messages and can't retrieve them. If I could reply, she would be so tired of me she wouldn't talk to me on Monday.*
- *It's too much if she had to serve 50 people. I don't want to overload my case manager.*

Several participants expressed that they have trouble organizing the daily tasks in their lives because they work, take care of children, grandchildren, or parents. The pager helps them remember to care for themselves.

- *The concept is good. The format is not effective as it should be. You can't dial 911. I don't know what the project is for. But as far as the pager is concerned, what worth is just a pager?*
- *For me, I have numerous doctors' appointments and I need it to coordinate those areas for me. It's taxing to think of those things and everything else. It's easy for you to say [it's limited] if you don't need it.*
- *The concern about our medicine is always there and other things are important too. It keeps us stronger.*
- *I work part-time and I can't keep appointments because I'm working. It's easier to keep up with me.*

Communications Before Receiving Pagers

Participants discussed how they kept in contact with members of their care team before they received pagers. While most of the participants kept in frequent contact with staff at the agencies where they went for assistance, some reported that staff sometimes had trouble contacting them.

- *Basically we used to talk on the phone a lot and home visits.*
- *Called everyday.*
- *By phone.*
- *He called me a lot to not be my case manager. Saw him more than them.*
- *We've been coming so long everyone knows us, the volunteers too. We've found this place to be a godsend.*
- *I would hide sometimes. Michael was my case manager and he would always say I gave him the wrong number.*
- *Send a letter if he needed me.*
- *Pretty much. I'd given my landlady's phone number. But be over at my grandparents and wouldn't retrieve messages until a day later. He's send a letter --"this is a third attempt". In the pantry he left a memo message that he needs to see me and that works for me. Looking for improvements.*
- *Pretty much so (hard to reach)*
- *Letters & phone calls (everyday)*
- *Manuel came to my house one day and dropped off food to me.*

Impacts on Compliance

Some participants reported that having the pagers made it easier to remember appointments; others already had systems in place, such as writing their appointments on a calendar, to help them remember. In addition, they noted that they did not receive reminder pages about appointments that they did not tell their case manager or prevention specialist about.

- *Yes. I have more concerns now (takes care of grandparents) and I need to do for me and take care of myself.*
- *No. Forgot appointment on Tuesday. Didn't have the pager – out of town. Friend came a day late to pick me up.*
- *When the pager goes off, maybe no or yes. I'll call if I have time. It's a time problem. The pager goes off and I go back to bed. I'm being honest.*
- *No, I write down appointments in my calendar.*
- *All I get is take meds and events. I write appointments on my calendar.*
- *I write on my calendar. I work part-time and have to take a day off.*

Participants were mixed as to whether their compliance with their treatment plan had improved since they received their pagers.

- *I take meds consistently. It's not effective, anyone can remind me.*
- *Yes, does it help? Sure.*

Desired Improvements

Participants were generally satisfied with the functions of the pager and the Technology Based Adherence Program, though they had some suggests for additional functionality. One participant expressed that he wanted the pager to do more, for instance call the police, ambulance or fire department directly. Another wanted better linkages between the pager and various doctors' appointments.

- *Why is it limited to that particular service? I don't want a pager to tell me to take my meds. It's not constructive. I like the concept, it's a good one (a reminder) but why limit it when it can do other things?*
- *Cell phone. I want a cell phone.*
- *There's always room for improvement.*
- *[Another participant] has a valid point. We could be out on the street away from a phone. I want to know I can dial my self help.*
- *E-mail, so my family can e-mail me.*
- *I don't really want a cell phone. I've gotten over being an abusive person calling everyone. If you need help you can do it from the pager. Unless it was restricted to a certain amount of numbers.*
- *Link it up to the doctors that we follow-up with.*
- *I don't go to the same doctor. I go to the VA clinic and I've seen so many [doctors] over there.*
- *We see the same doctor and they have a computer system called "Comet." It goes straight into the doctor's computer to communicate with him.*

Conclusions

Overall, focus group participants who have received pagers as part of the Technology Based Adherence Program are enthusiastic about the program, appreciate the pagers and the efforts to reach out to them that the pagers represent, and feel that the pagers have had some impact on their adherence to treatment plans. It is unknown whether the clients with pagers who did not attend the focus group feel as strongly or positively about the pagers.

While many of the participants in the focus group had frequent and regular contact with the agencies that served them before they received pagers, they noted that the pagers facilitated communication with the case manager. This may particularly be the case for clients without stable housing or a regular telephone number, but this cannot be assessed with certainty based on the clients who attended the group.

Some group participants had varying ideas about the purpose of the project. While most understood that the project would help with communications and remembering medications and appointments, they noted problems with using the pagers to communicate back to the case managers. At the time of the focus group, case managers were not able to view clients' replies to their pages.

Some participants wish that the pagers had additional features, and some noted that they were not paged for appointments they had not told their case managers about. Case managers should make a point of asking clients about upcoming appointments or events for which they would like reminder pages.

Focus Group Discussion Guide

Background	Earlier focus groups with end users suggested that pagers would be the preferred technology for improving adherence to treatment plans. These focus groups will elicit feedback from end users on their experiences with the pagers
Purpose	These focus groups will offer insights that can be used to refine design and implementation for similar projects in the future
Objective	Assess implementation: How have the clients felt about the way they got the pagers? What instruction did they receive? What would have made them more or less willing to use the pagers? Assess outcomes: Have the pagers helped clients communicate with case managers? Have the pagers helped clients remember appointments? Have the pagers helped clients take their medications on schedule? Address concerns: Confidentiality

Welcome (5 min)

Ground Rules and Purpose

Introduction and Warm Up (<10 min)

Name and whether you ever had a pager before you got one for the project

When did you find out you were going to get a pager for this project?

When did you receive your pager?

In-Depth Investigation (55 min)

Implementation (30-35 min)

What was explained to you about the pager project? Do you remember signing the informed consent form? Did you have any concerns? What? Were they addressed? How? Did anything about the project surprise you? What?

Do you always carry your pager with you? Why or why not? How do you feel about the pager? What would have made you feel more positively about the pager? Are there any changes you would like to see with the pager project?

How much instruction did you get about how to use it?

Do you feel like you know how to use it? How long did that take?

Outcomes (20-25 min)

How did your case manager get in touch with you before you got the pager? Was it easy or difficult for him or her to contact you? How often were you in contact with your case manager before you got the pager? How often are you in contact with your case manager since you got the pager? Has it made it easier to remember appointments?

How often do you get paged on your program pager? How was that set up? Do you feel you get too many pages, not enough pages or about the right number? What changes would you like to make to how often you get paged? How often do you respond to the pages you receive? Are there specific pages you don't respond to? Why?

How many of you receive pages reminding you to take your meds? Has it helped you remember to take your medications on schedule? How did you remember to take your

meds before you got the pager? How consistent were you – did you miss doses or take them late? How consistent are you now?

Conclusion and Summary (5 min)

Those are all my questions. Does anyone have any final concerns or ideas they'd like to discuss before we wrap up?

Summarize discussion.

Pager Tutorial (Abe – 15 min)

Access Community Health Network Technology Based Adherence Project

Documenting Internal Impacts: Key Informant Discussions with Collaborative Agencies' Staff

August 2004

Background

Access Community Health Network established the West Side Collaborative Care (WSCC) in response to the identified need for an integrated, networked service delivery system on Chicago's West Side. The collaborative represents three community health providers, one AIDS services organization, one community-based organization and two drug treatment providers.

The WSCC Technology Opportunity Program - Technology Based Adherence Project (TOP-TBAP), funded through the U.S. Department of Commerce, is a project with a two-fold purpose: to use web-based and wireless technology to facilitate referrals and information sharing among participating collaborative agencies and increase client adherence to treatment plans. TOP-TBAP is expected to impact both the clients enrolled in the technology study and the collaborative agencies developing and using the technology.

Ongoing data collection using the web-based *Equicare* system and agency records is one element used to assess the impacts of the project. The other element is focus groups or conversations with clients and agency staff.

In July 2003, key informant interviews were conducted with staff involved in the project at each agency. They suggested that agencies considered the project important and that staff felt the project furthered their mission, though a few reported that the project imposed additional burdens that diverted them from other work. As the *Equicare* system was rolled out, several agencies reported making more referrals, particularly to Haymarket, but most reported that the number of referrals they received did not increase significantly.

MCIC proposed a second set of key informant interviews to be conducted in July and August 2004. The purpose of this second set of key informant interviews with involved staff at each agency was to continue to document the internal impacts of the WSCC TOP-TBAP project on each agency and to get a sense of agencies' perceptions of the strengths and weakness and lessons learned from the project. In addition, it was an opportunity to explore two issues that arose during the course of the project: the low number of referrals documented in the *Equicare* system and staffing changes at a number of agencies participating in the project. Finally, the interviews were a means of collecting success stories and anecdotes to further enrich the evaluation.

Methodology

MCIC drafted the initial discussion guide to cover the topics of interest. Abraham Miller and Phaona Gray of Access Community Health Network approved the discussion guide. At the July WSCC meeting Melissa Kraus Schwarz, the project evaluation from MCIC, announced that she would contact representatives from each agency to schedule an interview. She also emailed representatives from each agency giving them advance

notice in July and again in August, asking them to select interview dates from among the options given.

Scheduling this second set of interviews was more challenging than scheduling the first set of interviews, and participation was lower. One agency, in which the primary contact was on medical leave for the duration of the interview period, and the secondary contact who had participated in the first interview was no longer working on the project, was not included in this set of key informant interviews. While several agencies had more than one staff member participating in the first round of key informant interviews, only two agencies had multiple representatives participate in the second round of key informant interview.

Findings from this set of key informant interviews appear below. Comments, edited for clarity, appear in italics.

Findings

Discussions with each agency started with an introduction to the purpose of the interview; agency representatives were asked to give their names and describe their involvement in the project.

Integration of Equicare System

Pagers integrated into services for study participants but referral module poorly integrated

Agency respondents were somewhat split in describing how well the *Equicare* system was integrated into their agencies' provision of services to clients. While some viewed it as well integrated into their system of caring for clients, others reported that it added a significant extra burden for staff. Generally, the pager module, which by definition was limited to the small number of clients who were entered into the system for the study, was better integrated than the referral module.

- *I think it's been pretty easy to integrate. We do see the clients on a fairly regular basis, and I've had some success contacting clients through the pagers who are more elusive through their case managers.*
- *I wouldn't say its something that's been greatly integrated. I'm the only person who knows how to use it. I don't use it that much.*
- *The clients I see are clients who walk in off the street. They're not in the system. We generate the referral by doing an intake form. We just keep on moving with the paper. It would be nice if we could enter the information into the system and then print that up to go into the folder. That would be a help and would alleviate us from having to do it twice. It wouldn't be a problem to put clients into the system then. It would be a problem because each agency uses different assessment forms and intakes.*

- *I think it's a great system, but the organizations that are in the system are typically not the places that our clients need services from, such as dentist, eyeglasses. I truly believe it's a great system.*

Only one of the agencies reported using the *Equicare* system for clients not enrolled in the TBAP project. The system, while almost uniformly described as easy-to-use or great, does not gather all the elements each agency needs for its own internal record keeping or external reporting. In addition, technical problems present a barrier to integrating the system into agencies' operations.

- The technical problems have been a barrier. Not being able to monitor client's activity. When we go into the system, it doesn't tell us client responses if they even responded to their pages. Not having that information doesn't allow me to use the system fully because I can't respond. The system has been down all week.

Staff Turnover

Effective management can smooth transition, but impacts often negative

Staff turnover occurred at five of the agencies in the past year, and this section of the interview documented what staffing changes occurred, how those transitions were managed, and what the impacts were on the project.

Day-to-day involvement in the project was limited towards the end of the study. Most respondents reported spending less than 10% of their time on the WSCC TOP-TBAP project, with only one, who was responsible for the largest number of clients, reporting that she spends almost 25% of her time on the project.

- It has potential, but not a big role at all. Less than 5%; that's both a positive and a negative. It's not a time consuming thing right now. Even if we were fully engaged it wouldn't be time consuming because it's easy to use when it's all working right.
- Since April. It plays quite a big role. I'm trying to think percentage wise what it would be, probably around 25%
- Maybe 5%. It's one of the many things I'm working on.

Conversations with representatives of these agencies revealed that staffing changes had significant impacts on the project at four of the five agencies. At the fifth agency, the changes were at the supervisory level, and several other people had the knowledge, training, and buy-in to minimize the impact of that change. At three agencies the changes had significant deleterious impacts on the project. The final agency managed the transition very effectively to minimize the negative impacts on the TBAP project.

Respondents from agencies with staffing changes generally report that the changes had a significant impact on the project. Clients had to get used to dealing with new staff members, and new staff members often struggled to get up to speed on the project.

- I think a lot of it was starting over. As much as clients want help and want services, the rapport is invaluable. They kind of had to get used to me, become familiar with me, understand why this woman is calling their house instead of Manuel. Going back to the beginning in terms of understanding what the project is about. Getting people to become more comfortable disclosing information. Initially, I had to keep Manuel's notes in front of me, and people were telling me other things. I think people did get more comfortable eventually that I'm not going to be judgmental.
- I would say the staff changes made a tremendous impact. The staff that left were with the project from the beginning. Now I'm the only person who knows what this project is. It left us...dragging behind the other organizations whose staff remained with the project throughout. I felt like sometimes it was over my head. I had to take the initiative to read about it and take the training. After the training it made sense. I didn't understand before that why we had the pagers. When we had the staff from the beginning we were even with everyone else, versus now.

Staffing changes caused problems in several ways. The first was in cases where there was simply a planned change in staffing as individuals' job descriptions changed. This generally caused a loss of knowledge of the project, and with backlogs of work common, training was often not a priority. This resulted in less activity using the system. In addition, replacement staff often dealt with different populations than the originally defined target-population for that agency, which made it more difficult to get up to speed on the TBAP project.

- It was probably as smooth as we could have made it. [The former staff member] was very helpful in getting me familiar with the systems and the paperwork. Abe got me trained almost immediately, and that was helpful. The easiest part was the computer; that wasn't a difficult transition. Just understanding what the program was about. You guys did a good job getting me up to speed. I attended a couple of meetings before the transition.
- The only difficulty we had was when Katrina left, there was problem replacing her, and scheduling training. With the change in staff we weren't up on it as much as we were in the past.

Staffing changes also impacted the project when the changes were part of larger organizational restructuring. In these cases, there were often delays in filling the vacated positions, and support for the project from upper management may have weakened. The delays in filling the positions resulted in longer periods of time with decreased activity on the *Equicare* system as knowledge of the project was lost and training postponed.

- In the change in staffing, passwords didn't get passed down to new staff appropriately. Incomplete training. We were vacant without staff for a while, and I didn't assertively make the new staff go get trained.
- Knowing that the project was coming to a close, it was less a priority. If we had known there was continuation, it would have encouraged the administration to make it more of a priority.

- *They didn't hand anything off; they just quit. I more or less picked up the pieces.*

Suggestions from staff new to the project: minimize need for duplicate data entry, review target populations

Some of the interview participants had suggestions for things they would have done differently if they had been involved with the program from the beginning. Two agencies would have pushed for a closer match between the data elements collected in the *Equicare* system and their own intake, referral, and progress forms in order to minimize the need to enter the same data in multiple systems. Two other agencies felt that the target-populations selected were not a good match for the program. Another wished that there had been someone in the agency whose job was to do all the data entry.

- *I would have dedicated more administrative time and made our IS department been more involved. I would have made a staff member be more responsive to the system, which would have reduced our barriers to data entry and using the system with the IS piece.*
- *I would have made it so that we could do all our intakes in the system, make copies of it and put it in our charts. We would have got more feedback then.*
- *Maybe I wouldn't have done the pager thing for the clients, from the point of view of the clients we have here. The pagers didn't really match any of the clients we have here now.*
- *I don't know how clients were selected for the program. I might have chosen clients a little differently. I think I would have chosen clients who previously expressed a need or an issue with missing dosages of their meds, clients maybe who weren't established and could have used the referrals.*

Referrals

Reasons why most agencies do not use *Equicare* for referrals: services not posted in system, extra work for data entry, delays in responses

*Only one agency reported frequently using the *Equicare* system to make referrals. The most common ways to make referrals was by telephone, using paper referrals forms, or using the two-way pagers distributed to each agency.*

*There are several reasons why agencies reported not using the *Equicare* system to make referrals:*

1. *Agencies to which they wanted to refer their clients were not in the system.*
2. *The clients were not in the system, and entering them into the system represented extra, unnecessary work.*
3. *The system was slower than picking up the phone or using the two-way pagers.*

Additionally, one agency reported that they didn't generally have to make a lot of referrals; most of their clients that were referred to them were already connected with all the services they needed.

- You would have gotten more activity in the system [if there were more services posted] because it would have captured more referrals, more shelters, more food pantry, more things of that nature.
- I just make referrals by telephone or I give clients a paper referral. They're not really in the system. Most of my clients are not in the system. The ones that are in the system are stable and haven't needed referrals.
- I think the clients in the study were really well established with care. I didn't have anyone in the study who was newly diagnosed. The people who needed treatment were in treatment. I think the program would be very helpful for the newly diagnosed.
- *I did those referrals through the system. And some just through the word of mouth. If the client was right here visibly, then, if they wanted to get into the methadone program I would just walk next door with them instead of putting them into the system.*

Even agencies that used the referral module very little had good things to say about the *Equicare* system for referrals. The additional feature that several people said would make the system more attractive for referrals was to have more agencies and services included in the system. Another suggested adding a popup feature that lets staff know that a referral is waiting on the system.

- *I think the system is fine. I don't see anything wrong with the Equicare system at all.*
- *I think the system is set up really nicely in terms of being able to receive information about the client and run through the criteria. All the information is there, and that's very useful.*
- If you're sending a referral through the system and you have a client waiting; it's not always answered immediately. I find the phone to be a little faster. Maybe when the referrals come though, maybe have a popup that the referral is there.

Client Impact

Positive impacts on adherence for the clients who are good matches for the program

Most of the respondents reported their impressions of the positive impacts of the adherence module on clients, though one felt that the pagers did not match the needs of her transient population. Another reported on her success in making a referral for drug treatment for a pregnant mom using the two-way agency pagers.

- For all the clients that I work with on the pager part of the program, they are ecstatic about it. They really enjoy the reminders. They don't have the problems they had in the past of having to remember to take their medicine or waking up to take their medicine. That is a thing of the past.

- The two-way pagers were quite successful. I was trying to get this pregnant mom into Haymarket. Kenis Williams was in a meeting. I paged her and let her know and we got her in right away.
- I don't think it's impacted my clients at all because the clients who use it, we haven't seen them enough for it to have an impact on them. We see them one day, the next day they're out of sight, incarcerated or whatever.
- One lady who states that she had issues with taking her medicines on time every time in the past; she had a problem with that prior to getting the pager. Now the pager reminds her to take the medicine every day at the same time. Her CD4 count went up.
- I was really surprised at the emotional impacts that the pager system has seemed to have, especially with clients who are not working, kind of just hanging out. It really built a lot of self-esteem and self-sufficiency in clients who were reliant on family members to remind them to take their medications. I think it was a source for some clients to realize that they are not as dependent as they thought they were. They don't need as much of the handholding that they had been receiving. After several clients had the pagers for a while they realized that they didn't have the problems keeping up with their medications and the pagers than they thought they did. With the medications becoming easier to take, the regimens have become easier, and a lot of the clients are recognizing that they do have a handle on it. Even the clients who didn't really need that type of structure have gained some confidence in themselves.

Referral module benefits transient clients who access services through outreach workers; newly-diagnosed clients and almost-stable clients benefit most from pagers

At several agencies there seemed to be a sense that not all of the clients enrolled in the study shared the characteristics of the type of client who would benefit the most from the technology. Some felt that their clients were too stable to get the full benefit from the project, and others felt that their clients were too transient. Generally, the referral module, to the extent that it allowed for instant confirmation of referrals, was considered to be very beneficial for outreach workers dealing with very unstable populations. Respondents also thought the referral module would be a great benefit for newly diagnosed clients. The pager module was considered to provide the most benefit to clients who were already pretty compliant but needed help to become stable on their medications.

- *The clients that would benefit most from the program would be the ones we meet at the needle exchange as well as the sex workers ... That's because they're so transient; we don't see them a lot, but we do see them occasionally at, and in the community.*
- *I think clients who are more stable, not near addiction or at least not actively using. They could have whatever illness, but don't have to be from place to place. Our clients are so transient. They would have to be a more stable type of client for this project to work. Our clients just have no responsibility going on at this point in their life.*

- *Newly diagnosed. I think people with diminished capacity for their memory, suffer from dementia, ones who are working and need to take midday medication.*
- *The clients that are compliant already, but the ones that are pretty much stable, trying to stabilize themselves with the medication, they would benefit from the pagers.*

Already-compliant or totally transient clients do not benefit from pagers

There was broad consensus on two types of clients who would not benefit from the TBAP project: those who are already stable and compliant and those who are totally transient.

- *I guess the ones that are already stable. And also the ones that are very transient, non-compliant. The ones that only come once in a blue moon, when they have a big problem.*
- *The clients we serve here. Transients. Clients who are still actively in their addiction. I don't see them hanging onto a pager or coming in for their appointments when they're supposed to. I don't see them doing that.*
- *Probably clients who are like ORS clients, who have a PA. A lot of them are bedridden and don't need the extra help. They have the resources to have reminders.*

Suggestions to improve system for clients: add more services; enhance communications with case managers

Though most respondents thought the system was generally excellent, there were a few suggestions for changes that would make the system more beneficial for clients. The first was to add more services. The second was to enhance the clients' ability to communicate with their case managers through the pagers. Another suggestion was to offer stipends to encourage clients to use the system.

- *I think the system was set up pretty well, especially with the consumer input at the beginning.*
- *I think add more services to the system. Expand it so it has all the services we need to refer people for.*
- *Just getting it fully functional. It would be nice for clients to be able to page me, or to be able to communicate with me from their doctor's office and tell me about appointments before they forget.*
- *Maybe if we offered stipends they'd be more willing to participate so there'd be something in it for them. We always have to do something to get clients to participate in anything.*

Lessons Learned

Change management requires buy-in from multiple levels at participating agencies; expectations must be aligned with capacities

There were several lessons learned by agencies participating in this project. The first two were known going into the project, but the true importance of these lessons became even clearer as the project went forward. These lessons both related to the challenges of change management; it is difficult for people to change the way they do things, particularly to implement a new computer system, and buy-in from many levels in organizations is necessary for successful change and collaboration. The other lesson learned was in managing expectations and keeping them in line with the capacities of the agencies and clients involved in the project. Finally, there were lessons learned on the technology side; capturing client responses did not work for the majority of the project duration.

Both the IT manager for the project and one of the representatives from Access Community Health Network had been involved in projects that included implementing new computer-based systems, and both realized that there would be significant challenges in getting people to use the system.

- *This is from before - it's very hard to get people to move over to a computer-based system. Getting people to actually use the system. It's an extra step; it's extra work. Even though we knew that in the long run, if it worked, it would save time.*
- *It's a change management issue, getting people to use a new system. The training is really vital. We've really focused on the training, on just giving people as many opportunities as they need to get comfortable on the system. You can't underestimate that.*

The second part of change management was securing adequate buy-in from all levels of the participating agencies. While the interpersonal relationships among the individuals who participated in the regular meetings were vital for the smooth functioning of the project, they were not sufficient to insure that an adequate level of attention was consistently paid to the project. In addition, clearer commitment from the lead agency to maintain the *Equicare* system after the initial pilot project may have encouraged partner agencies to make the necessary IT investments to allow their existing data systems to import common data elements from the *Equicare* system.

- *The collaboration and relationships is the key to making a project like this work. You need buy in at multiple agency levels. The buy-in is helpful, but the direct staff implementing it is key. Even if the administration, the admin needs to know what's going on so you don't run into what we ran into with the computer glitch, but all the administration support in the world doesn't make a difference if the staff can't work on the system.*
- *I would have had more involvement and buy in from the senior leadership at access, really getting out upper management to lean on the upper management*

at the other agencies. The buy-in really has to come from the top. I'm not sure how much institutional commitment there really was.

In terms of managing expectations, some agencies were disappointed by some of the limitations of the project. Clients did not always follow through with treatment plans, even with the help of the pagers. Staff did not always have the resources to make full use of the technology, and implementing the technology required the investment of significant staff time to meet the reporting requirements to evaluate the project. Finally, some agencies felt they really only benefited from one part of the project, such as the adherence module or the two-way agency pagers.

- *I think that for me, as much faith as I have in my clients, I have to remember that they're actively in their addiction, and I have to remember that they probably won't do the things that are necessary for them to do to make the project successful. They just didn't do it. Whatever it was I setup for them to do, they didn't do. That's to be expected, but maybe I just put too much expectation on them. It was too much for them as well.*
- *That's my only complaint. Having to do double paperwork for our folder and the system.*
- *I think it was a very good pilot project. I think it's a doable project, but I'm in agreement with Jerry about the components. When we initially got into the project it was about the pagers; that is what I believe is more important, especially because we're a one-stop shop. We have everything here except for the treatment part. I definitely used Haymarket a lot for clients not in the system, but using the phone, not the system.*

Suggestions: collect all information necessary to eliminate data entry duplication; add training opportunities

Respondents mentioned two main changes that would have made the project better. The first change was to make the system collect all the information needed for all the agency forms to eliminate duplicate data entry efforts. The second change was adding more training opportunities for new staff. Additionally, one respondent had problems with the pager distribution, which she described as torturous.

- *I think that if we had follow-up training. In the beginning there was training, but with new staff coming, the training was a crash course. I think if we had more TA training, it would have been better.*
- *More training. Even with all the resources we put into the trainings, I still don't think it was enough. I think people still had trouble with the technology, with really feeling comfortable with the technology.*
- *I'm not sure how distribution could have been more easily accomplished. It was incredibly difficult for no good reason. I would have liked to see that go a different way. It was torturous. I don't think clients were able to receive the full benefit of the pagers. I think a training on how to use them would have been beneficial. Even after Manuel left I found myself explaining the pagers and the program a*

whole lot, showing clients how to use the pagers. We're working with a population that really is not technology savvy and could have used a cheat sheet and more time to play with the pagers with someone showing them how to use the pagers.

Conclusions

Limited integration of Equicare system, particularly for referrals

This second round of key informant interviews revealed that at the end of the project the Equicare system was only partially integrated into the work of the participating agencies. One agency reported using the web-based referral module extensively, but most used only the two-way agency pagers or relied on telephone or paper referrals.

Partial success in adherence module

Some agencies were successful in deploying the adherence module to serve their clients, and their clients largely benefited from having the pagers. Two agencies were unable to distribute most of their pagers.

Impacts of staff turnover generally negative

Staff turnover significantly impacted the project's implementation at half the participating agencies. In general, these impacts were detrimental to the success of the project as they resulted in two agencies not distributing most of their pagers and several agencies not making full use of the adherence or referral modules.

Lessons learned: necessity of buy-in from all levels of organization, importance of ongoing training

Some important lessons were learned. The most significant was the absolute necessity of securing buy-in from all levels of an organization for a project of this type in order to ensure continuing organizational investment in making the changes required by the new web-based system. In addition, clearer commitment from the lead agency to maintain the *Equicare* system after the initial pilot project may have encouraged partner agencies to make the necessary IT investments to allow their existing data systems to import common data elements from the *Equicare* system. Ongoing training is also vital in this effort because of staffing changes over the course of a project of this type.

Numerous successes for individual clients

Despite the challenges, there were a number of success stories for individual clients who received referrals when then needed them, were stabilized on their medication regimens, and gained confidence in their ability to manage their HIV treatment. Individuals and agencies built stronger relationships that helped them better serve their clients.

Discussion Guide

Process Evaluation - Agency Impacts

1. Introduction

- a. Purpose, taping
- b. Names and titles

2. Integration

- a. Tell me how your agency has done in integrating the Equicare system into your everyday operations in providing services to clients? (Does it serve any clients outside of the TOP project? Does it duplicate parts of an existing system?) What challenges did you have to overcome?
- b. How integral is the Equicare system to the services you provide to clients?
- c. How does {your agency} support the project?

3. Staff Turnover

- a. How long have you worked on the TBAP project? How big of a role does this project play in your day-to-day work?
- b. Have other people at your agency who are not involved with this call worked on the project?
- c. How did they hand off their involvement in the project? How was that managed? Do you feel that you received enough support for the project? From whom? How?
- d. What were the challenges of picking up the project in the middle?
- e. What would you say the impacts have been of the change in who is involved in the project from your agency?
- f. Are there things you would have done differently if you had been involved from the beginning?

4. Referrals

- a. How do you make referrals to other WSCC agencies? Do you use the Equicare system for referrals to other WSCC agencies? Why/why not?
- b. Are there features that would make the system more attractive for referrals? What are they?

5. Client Impact

- a. What are your impressions on how the system has impacted your clients? Do you have any stories or anecdotes you'd like to share?
- b. What types of clients would benefit the most from the system?
- c. What types of clients would benefit least?
- d. Are there changes that would make the project more beneficial for clients?

6. Lessons Learned

- a. What do you see as the lessons learned from this project?
- b. What changes would have made the project better?

7. Those are all my questions. Is there anything you would like to add?

TBAP Provider Technology and Referral Assessment Codebook

In order to measure the impacts of the TBAP project on agencies' use of and comfort with technology and the efficiency of their referrals processes, MCIC created a brief survey to be administered before the technology was rolled out and at the end of the project.

The baseline data were collected during the mandatory training sessions that taught agency staff how to use the *Equicare* system. The final survey was distributed on August 18, 2004 at the monthly WSCC-TOP meeting, with participants asked to complete the survey themselves and to distribute it to the people at their agency who had been trained on the *Equicare* system. A total of 26 respondents completed the baseline assessment, and 11 respondents completed the final assessment.

The relatively low response rate for the final assessment can be attributed to several factors. The most significant factor was that the survey was distributed during a meeting attended by a representative from each agency rather than at a series of trainings attended by several people from each agency. The agency representatives were responsible for distributing the final survey to their coworkers and having them fax it back to MCIC. Representatives attending the monthly meeting completed the majority of the final surveys.

The second factor is staff turnover at several agencies; several direct service staff or administrators who were trained in the *Equicare* system have left their agencies or may no longer be involved with the TBAP project. Although a number of people who completed the baseline survey at the training sessions have left their agencies, the number of final surveys completed was less than anticipated.

Percentages for each item and annotations explaining the implications of the changes appear in the codebook below. Chi-square tests were conducted for all items to highlight statistically significant differences. Only two items were statistically significant with $p \leq 0.05$, but given the small number of completed surveys for the baseline and final assessments this is not surprising. While not statistically significant, the changes do seem to represent positive impacts on the technology usage and the efficiency of referrals for participating agency staff.

1. How many hours per week do you use a computer?
Baseline: 20% Less than 5 16% 5 – 10 16% 11-20 48% 21 or more
Final: 9% Less than 5 18% 5 – 10 9% 11-20 64% 21 or more

These changes are not statistically significant and may reflect differences in the people completing the survey rather than actual changes in computer usage in the original cohort completing the survey. However, they do reflect that fact that the most involved staff at the end of the project were those with the most comfort with technology, as indicated by their heavy computer usage.

2. Do you have a personal email address? Baseline: 77% Yes 23% No
Final: 90% Yes 10% No

This increase, while not statistically significant, also indicates that those who completed the final survey were more likely to use technology than the original sample.

3. Do you have email at work? Baseline: 85% Yes 15% No => **Skip to Question 6**

Final: 100% Yes 0% No => **Skip to Question 6**

IF YES: 3a. Are you using a free or personal email account for work-related email?

Baseline: 64% Yes 36% No Final: 29% Yes 71% No

The increase in Item 3 and the decrease in 3a may reflect the impacts of the technology assistance provided as part of the TBAP project. As part of the TBAP project, all the agencies' computer systems and internet access were assessed and upgraded as necessary to ensure that all agencies in the collaborative would be able to use the web-based referral system. While the changes are not statistically significant, and may partly reflect the change in who actually completed the final survey; they seem to reflect true changes. Fourteen respondents in the initial survey reported using a free or personal email account for work-related email; in the final survey only two respondents reported using a free or personal account for work.

4. How often do you use email at work?

Baseline	Final
71% Several times a day	80% Several times a day
19% Once or twice, most days	20% Once or twice, most days
5% A few times a week	0% A few times a week
5% Once a week or less	0% Once a week or less

While the magnitude of changes in the frequency that respondents use email at work is small, and the changes are not statistically significant, it is interesting to note that all of the respondents who have email at work use it at least once or twice on most days.

5. What do you use email for at work? (Check all that apply)

Baseline	Final
82% Communicate with people in your organization	100% Communicate with people in your organization
36% <i>Communicate with other organizations regarding clients</i>	80% <i>Communicate with other organizations regarding clients</i>
64% <i>Updates on work related activities</i>	100% <i>Updates on work related activities</i>
73% Networking (Finding out about resources, trainings, etc.)	100% Networking (Finding out about resources, trainings, etc.)
18% Communicate with clients (Follow-up on services, get feedback, etc.)	40% Communicate with clients (Follow-up on services, get feedback, etc.)
50% Personal correspondence	40% Personal correspondence
9% Other	10% Other

There were statistically significant increases in the percent of respondents using email at work to communicate with other organizations regarding clients and for updates on work-related activities. All respondents to the final survey reported using email to communicate with people in their own organization and for networking, substantial increases from the 82% and 73% respectively reporting those uses for work email in the baseline survey. In addition, the percent that reported using email at work to communicate with clients more than doubled, from 18% in the baseline survey to 40% in the final survey.

6. Do you use Instant Messenger?	Baseline:	32% Yes	68% No
	Final:	30% Yes	70% No

There was no appreciable change in the percentage of respondents reporting using Instant Messenger between the baseline survey and the final survey.

7. Do you have a cell phone?	Baseline:	100% Yes	0% No
	Final:	91% Yes	9% No

There was a slight non-statistically significant decrease in the percentage of respondents who have a cell phone. Given the near ubiquity of cell phones, it is unlikely that this small decrease represents any decrease in comfort with technology.

8. What is the average time to initiate and confirm a referral using your current procedures?

Baseline	Final
36% Less than ½ day	60% Less than ½ day
41% ½ - 1 day	20% ½ - 1 day
18% More than 1 day	20% More than 1 day
5% More than 1 week	0% More than 1 week

The percentage of respondents reporting that it took less than half a day to initiate and confirm a referral almost doubled, from 36% in the baseline survey to 60% in the final survey. The percent reporting that it took between half a day and one day decreased by half, from 41% in the baseline survey to 20% in the final survey. No respondents reported that it took more than a week on average to initiate and confirm a referral in the final survey. These improvements almost certainly reflect the deployment of the *Equicare* system and the two-way pagers.

9. How cumbersome is it to contact case managers/providers at other agencies to make a referral?

Baseline	Final
13% Not at all cumbersome	36% Not at all cumbersome
78% Somewhat cumbersome	55% Somewhat cumbersome
9% Very cumbersome	9% Very cumbersome

The percentage reporting that contacting case managers and providers at other agencies to make a referral not at all cumbersome almost tripled, from 13% in the baseline survey to 36% in the final survey. The percent reporting that it was somewhat cumbersome decreased from 78% in the baseline survey to 55% in the final survey. This change almost certainly reflects the implementation of the *Equicare* system and the two-way pagers.

10. The amount of time it takes to coordinate referrals compromises my ability to effectively serve my clients.

Baseline	Final
17% Strongly Disagree	20% Strongly Disagree
21% Disagree Somewhat	60% Disagree Somewhat
46% Agree Somewhat	10% Agree Somewhat
17% Strongly Agree	10% Strongly Agree

The percent of respondents agreeing that the amount of time it takes to coordinate referrals compromised their ability to serve their clients decreased from 63% in the baseline survey to 20% in the final survey. While some of this change may reflect differences in the populations completing the baseline and final surveys, it is very likely that the improvements reflect the implementation of the *Equicare* system.

Changes in technology usage between the baseline survey and the final survey reflect both the differences in the populations completing each survey and the effects of the investments in technology and training for the TBAP project. While it is not possible to distinguish between these two factors in this analysis, it is reasonable to believe that both play a factor.

The changes in the perceived efficiency of referrals, while not statistically significant, are likely the result the result of the technology and training investments of the TBAP project. Another factor increasing the efficiency of referrals is that representatives from agencies participating in the project have developed stronger relationships with each other as a result of working together on the project. This makes referrals more efficient because referring agencies know whom to call, and receiving agencies may be more likely to make resources available.

Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
ACCESS	<ul style="list-style-type: none"> • Male IDU's • Female IDU's • MSM's 	15	<ul style="list-style-type: none"> • Decrease in drug use • Fewer sex partners • Increase in safer sex practices 	Number of visits to needle exchange No new STDS	Number of visits to needle exchange: _____ STD tests (Gonorea, Chlamydia, syphilis, HIV.) performed on-site

Baseline Objective Data 1/1/03- 3/31/03	<u>STD Tests</u>	Positive	Negative
Number of visits to needle exchange 1/1/03-3/31/03: _____	Gonorrhea	+	-
	Chlamydia	+	-
	Syphilis	+	-
	HIV	+	-
Objective Data 6/1/03- 8/31/03	<u>STD Tests</u>	Positive	Negative
Number of visits to needle exchange 6/1/03- 8/31/03: _____	Gonorrhea	+	-
	Chlamydia	+	-
	Syphilis	+	-
	HIV	+	-
Objective Data 1/1/04 - 3/31/04	<u>STD Tests</u>	Positive	Negative
Number of visits to needle exchange 1/1/04 - 3/31/04: _____	Gonorrhea	+	-
	Chlamydia	+	-
	Syphilis	+	-
	HIV	+	-
Objective Data 6/1/04 – 8/31/04	<u>STD Tests</u>	Positive	Negative
Number of visits to needle exchange 6/1/04 – 8/31/04: _____	Gonorrhea	+	-
	Chlamydia	+	-
	Syphilis	+	-
	HIV	+	-

Client Name: _____
Date of Birth: ____/____/____ (MM/DD/YYYY)

Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
Vital Bridges	HIV (+) Adults over 18.	40	<ul style="list-style-type: none"> Increase in detox/drug treatment Group attendance Keeping appointments with case manager Increased number of appointments for care/support services 	<p>Attending appointments with case manager and supportive services</p> <p>Attending group</p> <p>No new STDs</p>	<p>Appointments kept as scheduled 1/1/03-3/31/03 /appointments total over 1/1/03-3/31/03</p> <p>Number of group sessions attended 1/1-3/31</p> <p>STD Tests: Gonorea, Chlamydia, syphilis</p>

Baseline Objective Data 1/1/03- 3/31/03				<u>STD Tests</u>	Positive	Negative
Number of appointments kept as scheduled (1/1/03-3/31/03): _____				Gonorrhea	+	-
Number of appointments scheduled (1/1/03-3/31/03): _____				Chlamydia	+	-
Number of group sessions attended 1/1/03-3/31/03: _____				Syphilis	+	-
Objective Data 6/1/03- 8/31/03				<u>STD Tests</u>	Positive	Negative
Number of appointments kept as scheduled (6/1/03-8/31/03): _____				Gonorrhea	+	-
Number of appointments scheduled (6/1/03-8/31/03): _____				Chlamydia	+	-
Number of group sessions attended 6/1/03-8/31/03: _____				Syphilis	+	-
Objective Data 1/1/04 - 3/31/04				<u>STD Tests</u>	Positive	Negative
Number of appointments kept as scheduled (1/1/04-3/31/04): _____				Gonorrhea	+	-
Number of appointments scheduled (1/1/04-3/31/04): _____				Chlamydia	+	-
Number of group sessions attended 1/1/04-3/31/04: _____				Syphilis	+	-
Objective Data 6/1/04- 8/31/04				<u>STD Tests</u>	Positive	Negative
Number of appointments kept as scheduled (6/1/04-8/31/04): _____				Gonorrhea	+	-
Number of appointments scheduled (6/1/04-8/31/04): _____				Chlamydia	+	-
Number of group sessions attended 6/1/04-8/31/04: _____				Syphilis	+	-

Client Name: _____
Date of Birth: ____/____/____ (MM/DD/YYYY)

Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
Genesis House	Women in Recovery	10	<ul style="list-style-type: none"> Group attendance Counseling sessions Completion of GED program Employment LTRR No Drug use 	Attends groups Attends counseling Completes GED Negative drug tests	<i>Number of group sessions attended 1/1-3/31</i> <i>Number of counseling sessions attended 1/1-3/31</i> <i>Number of GED classes attended 1/1-3/31</i> <i>When was your last drug test? Was it positive or negative?</i> <i>STD tests</i>

Baseline Objective Data 1/1/03- 3/31/03 When was your last drug test? ____/____/____ (MM/DD/YYYY) Was it positive or negative? (Circle One): + -- Number of group sessions attended 1/1/03-3/31/03: _____ Number of GED classes attended 1/1/03-3/31/03: _____	<u>STD Tests</u> Gonorrhea Chlamydia Syphilis Hepatitis C HIV	Positive + + + + +	Negative - - - - -
Objective Data 6/1/03- 8/31/03 When was your last drug test? ____/____/____ (MM/DD/YYYY) Was it positive or negative? (Circle One): + -- Number of group sessions attended 6/1/03-8/31/03: _____ Number of GED classes attended 6/1/03-8/31/03: _____	<u>STD Tests</u> Gonorrhea Chlamydia Syphilis Hepatitis C HIV	Positive + + + + +	Negative - - - - -
Objective Data 1/1/04 - 3/31/04 When was your last drug test? ____/____/____ (MM/DD/YYYY) Was it positive or negative? (Circle One): + -- Number of group sessions attended 1/1/04-3/31/04: _____ Number of GED classes attended 1/1/04-3/31/04: _____	<u>STD Tests</u> Gonorrhea Chlamydia Syphilis Hepatitis C HIV	Positive + + + + +	Negative - - - - -
Objective Data 6/1/04 – 8/31/04 When was your last drug test? ____/____/____ (MM/DD/YYYY) Was it positive or negative? (Circle One): + -- Number of group sessions attended 6/1/04-8/31/04: _____ Number of GED classes attended 6/1/04-8/31/04: _____	<u>STD Tests</u> Gonorrhea Chlamydia Syphilis Hepatitis C HIV	Positive + + + + +	Negative - - - - -

Client Name: _____ Date of Birth: ____/____/____ (MM/DD/YYYY)
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Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
Haymarket Center	<ul style="list-style-type: none"> Hepatitis C Positive Drug Users HIV (+) Post Released HIV (+) Substance Users 	18	<ul style="list-style-type: none"> Increased recovery time Increased use of condoms and fewer # of sex partners Stable housing Getting a sponsor & support group Increased screenings & medical care 	<ul style="list-style-type: none"> Length of recovery Maintains housing Kept appointments Secures medical care 	<ul style="list-style-type: none"> Number of 12-step meetings logged 1/1-3/31 When was your last drug test? +/- Appointments kept as scheduled 1/1/03-3/31/03 /appointments total over 1/1/03-3/31/03 When did you last see a doctor or health care provider?

<p>Baseline Objective Data 1/1/03- 3/31/03</p> <p>When was your last drug test? ___/___/___ Was it positive or negative? + --</p> <p>Number of 12-step meetings in client log 1/1/03-3/31/03: _____</p> <p>In supportive housing or has lease? Yes No Date of last doctor visit: ___/___/___ (MM/DD/YYYY)</p> <p>Appointments kept as scheduled (1/1/03-3/31/03): _____ Appointments scheduled (1/1/03-3/31/03): _____</p>
<p>Objective Data 6/1/03- 8/31/03</p> <p>When was your last drug test? ___/___/___ Was it positive or negative? + --</p> <p>Number of 12-step meetings in client log 6/1/03-8/31/03: _____</p> <p>In supportive housing or has lease? Yes No Date of last doctor visit: ___/___/___ (MM/DD/YYYY)</p> <p>Appointments kept as scheduled (6/1/03-8/31/03): _____ Appointments scheduled (6/1/03-8/31/03): _____</p>
<p>Objective Data 1/1/04 - 3/31/04</p> <p>When was your last drug test? ___/___/___ Was it positive or negative? + --</p> <p>Number of 12-step meetings in client log 1/1/04-3/31/04: _____</p> <p>In supportive housing or has lease? Yes No Date of last doctor visit: ___/___/___ (MM/DD/YYYY)</p> <p>Appointments kept as scheduled (1/1/04-3/31/04): _____ Appointments scheduled (1/1/04-3/31/04): _____</p>
<p>Objective Data 6/1/04 – 8/31/04</p> <p>When was your last drug test? ___/___/___ Was it positive or negative? + --</p> <p>Number of 12-step meetings in client log 6/1/04-8/31/04: _____</p> <p>In supportive housing or has lease? Yes No Date of last doctor visit: ___/___/___ (MM/DD/YYYY)</p> <p>Appointments kept as scheduled (6/1/04-8/31/04): _____ Appointments scheduled (6/1/04-8/31/04): _____</p>

<p>Client Name: _____</p> <p>Date of Birth: ___/___/___ (MM/DD/YYYY)</p>
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Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
Lawndale Christian Health Center	HIV Positive Substance Abusers	4-10	<ul style="list-style-type: none"> Increased attendance at support groups Keeping appointments with case manager and physician Increased number of appointments for care/support services 	Keeps medical appointment ER visits Outreach contact	Appointments kept as scheduled 1/1/03-3/31/03 /appointments total over 1/1/03-3/31/03 Number of ER visits 1/1-3/31/03 # of contacts 1/1-3/31/03 /contact attempts by program staff 1/1-3/31/03

Baseline Objective Data 1/1/03- 3/31/03 Number of appointments kept as scheduled (1/1/03-3/31/03): _____ Number of appointments scheduled (1/1/03-3/31/03): _____ Number of ER visits 1/1/03-3/31/03: _____ Number of contacts 1/1/03-3/31/03: _____ Number of contact attempts 1/1/03-3/31/03: _____
Objective Data 6/1/03- 8/31/03 Number of appointments kept as scheduled (6/1/03-8/31/03): _____ Number of appointments scheduled (6/1/03-8/31/03): _____ Number of ER visits (6/1/03-8/31/03): _____ Number of contacts (6/1/03-8/31/03): _____ Number of contact attempts (6/1/03-8/31/03): _____
Objective Data 1/1/04 - 3/31/04 Number of appointments kept as scheduled (1/1/04-3/31/04): _____ Number of appointments scheduled (1/1/04-3/31/04): _____ Number of ER visits (1/1/04-3/31/04): _____ Number of contacts (1/1/04-3/31/04): _____ Number of contact attempts (1/1/04-3/31/04): _____
Objective Data 6/1/04 - 9/30/04 Number of appointments kept as scheduled (6/1/04-8/31/04): _____ Number of appointments scheduled (6/1/04-8/31/04): _____ Number of ER visits (6/1/04-8/31/04): _____ Number of contacts (6/1/04-8/31/04): _____ Number of contact attempts (6/1/04-8/31/04): _____

Client Name: _____ Date of Birth: ____/____/____ (MM/DD/YYYY)
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Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
PCC Community Wellness	Substance abusers with chronic asthma/physical psychosocial issues	10	<ul style="list-style-type: none"> Increased attendance at support groups Keeping appointments with case manager and physician Increased number of appointments for care/support services 	Keeps medical appointment ER visits Outreach contact	Appointments kept as scheduled 1/1/03-3/31/03 /appointments total over 1/1/03-3/31/03 Number of ER visits 1/1-3/31/03 # of contacts 1/1-3/31/03 /contact attempts by program staff 1/1-3/31/03

Baseline Objective Data 1/1/03- 3/31/03 Number of appointments kept as scheduled (1/1/03-3/31/03): _____ Number of appointments scheduled (1/1/03-3/31/03): _____ Number of ER visits 1/1/03-3/31/03: _____ Number of contacts 1/1/03-3/31/03: _____ Number of contact attempts 1/1/03-3/31/03: _____
Objective Data 6/1/03- 8/31/03 Number of appointments kept as scheduled (6/1/03-8/31/03): _____ Number of appointments scheduled (6/1/03-8/31/03): _____ Number of ER visits (6/1/03-8/31/03): _____ Number of contacts (6/1/03-8/31/03): _____ Number of contact attempts (6/1/03-8/31/03): _____
Objective Data 1/1/04 - 3/31/04 Number of appointments kept as scheduled (1/1/04-3/31/04): _____ Number of appointments scheduled (1/1/04-3/31/04): _____ Number of ER visits (1/1/04-3/31/04): _____ Number of contacts (1/1/04-3/31/04): _____ Number of contact attempts (1/1/04-3/31/04): _____
Objective Data 6/1/04 – 8/31/04 Number of appointments kept as scheduled (6/1/04-8/31/04): _____ Number of appointments scheduled (6/1/04-8/31/04): _____ Number of ER visits (6/1/04-8/31/04): _____ Number of contacts (6/1/04-8/31/04): _____ Number of contact attempts (6/1/04-8/31/04): _____

Client Name: _____ Date of Birth: ____/____/____ (MM/DD/YYYY)
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Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
Test Positive Aware Network	HIV+ African American males with drug/health care compliance issues	10	<ul style="list-style-type: none"> Increased education and prevention Decrease in drug use Gets regular medical care 	Attends BUS support group Clean drug tests Regular doctor visits	Number of BUS group meetings attended 1/1-3/31 Date of last drug test? +/-? Date of last Doctor visit?

Baseline Objective Data 1/1/03- 3/31/03 When was your last drug test? ____/____/____ Was it positive or negative? + -- Number of BUS meetings attended 1/1/03-3/31/03: Date of last doctor visit: ____/____/____ (MM/DD/YYYY)
Objective Data 6/1/03- 8/31/03 When was your last drug test? ____/____/____ Was it positive or negative? + -- Number of BUS meetings attended 6/1/03- 8/31/03: Date of last doctor visit: ____/____/____ (MM/DD/YYYY)
Objective Data 1/1/04 - 3/31/04 When was your last drug test? ____/____/____ Was it positive or negative? + -- Number of BUS meetings attended 1/1/04-3/31/04: Date of last doctor visit: ____/____/____ (MM/DD/YYYY)
Objective Data 6/1/04 – 8/31/04 When was your last drug test? ____/____/____ Was it positive or negative? + -- Number of BUS meetings attended 6/1/04- 8/31/04: Date of last doctor visit: ____/____/____ (MM/DD/YYYY)

Client Name: _____ Date of Birth: ____/____/____ (MM/DD/YYYY)
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Agency	"At Risk" Population You Will Serve	Number to be Served	Measurable Indicators for Positive Behavior Change	Objective Measured	Baseline Data Collection Items
Family Guidance	Heroin addicts on methadone	5	<ul style="list-style-type: none"> Regular attendance at Family Guidance No heroin use 	<ul style="list-style-type: none"> Regular attendance at Family Guidance No heroin use 	Number of visits to Family Guidance 1/1-3/31 Date of last drug test? +/-? Date of last Doctor visit?

Baseline Objective Data 1/1/03- 3/31/03 When was your last drug test? ____/____/_____ Number of Family Guidance Visits /1/03-3/31/03:	Was it positive or negative? + --
Objective Data 6/1/03- 8/31/03 When was your last drug test? ____/____/_____ Number of Family Guidance Visits 6/1/03-8/31/03:	Was it positive or negative? + --
Objective Data 1/1/04 - 3/31/04 When was your last drug test? ____/____/_____ Number of Family Guidance Visits 1/1/04-3/31/04:	Was it positive or negative? + --
Objective Data 6/1/04 – 8/31/04 When was your last drug test? ____/____/_____ Number of Family Guidance Visits 6/1/04-8/31/04:	Was it positive or negative? + --

Client Name: _____
Date of Birth: ____/____/____ (MM/DD/YYYY)

Technology Based Adherence Project (TBAP)
Informed Consent For Research Subject
Principal Investigator: Dr. Elizabeth Calhoun
Sponsor: U.S. Department of Commerce & Centers for Disease Control

INTRODUCTION/PURPOSE: The Technology Based Adherence Project (TOP-TBAP) will evaluate the use of technology to help address the issue of non-adherence to referrals and treatment plans among clients of human service agencies serving the five medically underserved Chicago communities (Austin, East & West Garfield Park, Near West Side, and North Lawndale). Our mission is to increase accessibility to comprehensive health care services for persons affected by HIV, STDs, TB and substance use disorders. Through the use of computers, case management software, & pagers, this project will allow the West Side Collaborative Care Agencies (a coalition of eight human services agencies which includes – Access Community Health, Family Guidance Center, Genesis House, Haymarket Center, Lawndale Christian Health Center, PCC Community Wellness, Test Positive Aware Network (TPAN), and Vital Bridges) to share key patient information in order to facilitate case coordination, patient access to services and continuity of care. The study will involve 75-150 subjects and will last two (2) years.

PROCEDURE: If you decide to participate in this study, you may be asked to fill out a brief questionnaire, asked to participate in focus groups and/or individual interviews, and asked to sign a consent form to have your information stored & shared electronically among the 8 different agencies that comprise the West Side Collaborative Care. In addition, as part of this study you may receive a text pager. This pager will allow your case manager to remind you of any appointments, when to take medication, or provide messages of encouragement while participating in the study. There is no cost to you to participate in this study nor will you receive any financial benefits.

RISKS: If at any time you feel uncomfortable with this study, you may elect to be removed from the study and ask to have your information removed from the TBAP computer system without penalty or loss of services provided.

BENEFITS: *Participation in this study will have long-term, positive effects on local communities, human service providers and their clients. Expected outcomes include (1) improved patient access to multiple agencies for services; (2) improved patient adherence to referrals and treatment plans; and (3) a way for human service agencies to improve the overall health of patients and their communities.*

CONFIDENTIALITY: All client information used for this study will be held with strict HIPAA confidentiality & security laws. If the results of the study are published, subjects will not be identified by name. All electronic forms of client information will be secured by passwords on TBAP's computerized system. Only authorized individuals will have access to the client's information. Data shared among the different eight (8) agencies will be encrypted for security purposes.

QUESTIONS: If you have any questions concerning your rights as a research subject while on this study, please contact Ms. Judith Waterston, President and Chief Executive Officer at (773) 257-6435. If you have any questions concerning this study, please contact Mr. Abraham Miller, Access Community Health Network (773) 257-5804.

AGE REQUIREMENTS: *Subjects must be at least eighteen (18) years of age and be infected by either HIV, STDs, TB or have a substance abuse disorder.*

TERMINATION: *Access Community Health Network and the West Side Collaborative Care Agencies have the right to terminate any individual from this study for the following reasons (1) theft of study equipment (i.e. text pager) and/or medical supplies, (2) threats of violence or physical harm towards employees or staff of the West Side Collaborative Care agencies, (3) imprisonment or (4) any reason deemed necessary by my case manager or any representative of the West Side Collaborative Care.*

DISCLOSURE: *This study will record HIV identifiers, which may be shared among the eight (8) agencies of the West Side Collaborative Care to help facilitate the management of care. This information will be kept in the client's chart and TBAP's computerized system and only the outreach team, case management team, director of research and evaluation, project manager, and project coordinator will have access to the information.*

Please have the Client read and initialize the following:

_____ *I understand that my participation in this study is strictly voluntary and at no costs to me. I further understand that I will receive no financial benefits for my participation in this study.*

_____ *I understand that at any time I feel uncomfortable with this study, I may elect to be removed as a participant of this study and ask to have my information removed from the computer system without (1) losing my right to services, (2) penalty or (3) loss of services provided.*

_____ *I understand that as a participant of this study, I may be asked to fill out questionnaires, be part of focus groups and/or individual interviews.*

_____ *I understand that as a participant of this study, I will be required to sign a consent form to have my information stored and shared electronically (on a computer) with the eight (8) different agencies that form the West Side Collaborative Care. I further understand that my information will be secured by passwords and only authorized personnel from these agencies will have access to my information.*

_____ *I understand that as a participant of this study, all of my information will be used for this study and will be held with strict confidentiality and security laws. If the results of this study are published, my identifying information (such as name, address, etc.) will NOT be used.*

_____ *I understand that as a participant of this study, I may receive a text pager, which is of no cost to me and is the property of the West Side Collaborative Care. The pager will be used to receive reminder messages from my case manager. If at anytime, I elect to leave the study or I am asked by my case manager to return the pager, I will return the pager in working condition.*

_____ *I understand that as a participant of this study, I must be at least eighteen (18) years of age, and be infected by either HIV, STD, TB or have a substance abuse disorder.*

_____ *I understand that I may be terminated/released from the study for the following reasons: (1) theft of study equipment (i.e. pagers, supplies) (2) threats of violence or physical harm towards staff members or clients, (3) imprisonment or (4) any reason deemed necessary by my case manager or any representative of the West Side Collaborative Care.*

I have read all of the above information and I am willing to participate in this study. I understand my participation in this study is voluntary and if I do not wish to participate in this study, I will not be penalized or lose any entitled benefits. I may also discontinue participation at any time without penalty or loss of benefits. I will only be asked to (1) complete a withdrawal request form and (2) return any equipment (i.e. text pager) given to me as part of this study. I understand that I will receive no financial benefit from participating in this study and participation in this study is at no cost to me. I have been given a copy of this consent form for my records.

Comments: _____

Date

Agency Name

Signature of Client

Printed Name of Client

Signature of Agency Worker

Printed Name of Agency Worker

Please Note: This consent form is valid till December 31, 2004.