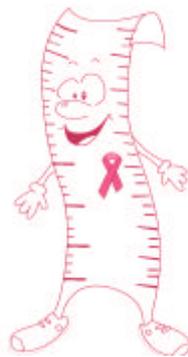# McMaster University
Hamilton, Ontario, Canada

PAPER C02-1

**INFORMATION MANAGEMENT
PROJECT: MACRO #4**

**MOHLTC REPORTING FORM ACTIVITIES
ASO TEMPLATES AND DATABASES
ASSESSMENT ACTIVITIES
LARGE DATABASE EVALUATIONS**

**Jacqueline Roberts
Gina Browne
Greg Robinson**

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CLEAR UNIT: MACRO PROJECT: "Developing CLEAR Information"

INFORMATION MANAGEMENT PROJECT

Authors: Jacqueline Roberts, Gina Browne, and Greg Robinson

ABSTRACT

Ontario's community-based AIDS organizations have become leading participants in the planning and decision making regarding the prevention of the spread of HIV and the delivery of programs for people infected and affected by HIV.

Many of these organizations sought support for gathering or accessing data, analysing data, interpreting the analysis and then understanding and using this knowledge to support future activities in their organization. The AIDS Bureau, MOHLTC, encouraged the CLEAR Unit to collaborate and offer support to AIDS service organizations as they developed methods to manage data. Thus, this Macro project on Information Management was developed to empower community organizations to develop information technologies for the purpose of using information to inform policy decisions.

While some ASOs currently possess the resources and skills to effectively manage important data, others need help in becoming more self-sufficient in this field of information technology. Some 23 AIDS Service Organizations have been assessed or assisted by the Information Management Team. Eleven databases or templates have been developed for ASOs. Many have been field-tested. Results indicated usefulness of these templates and databases. Dissemination activities have bee undertaken and these templates and databases have been offered to other AIDS organizations for use.

The ASOs complete a quarterly report for the MOHLTC. This report was developed as a collaborative effort between the CLEAR Unit and the Ministry so that ASOs can report their statistics on EXCEL spreadsheets via email. This activity was pre tested in 2000 and carried out in 2001 and 2002. The CLEAR Unit participated in workshops during 2001 and 2002 with ASOs that use this reporting form.

OHTN, HIIP meetings were attended by CLEAR Unit Investigators and the Central Research Database was examined and followed with interest by CLEAR Unit, with the hope that this database will be useful in the future to help answer some of the ASO research questions.

INTRODUCTION

The Ontario Ministry of Health, under the auspices of the AIDS Bureau, provides a community development approach in preventing the spread of HIV infection and providing support for people infected and affected by HIV/AIDS (CBAESP Activity Report, 1995). This community mobilization includes strategies to ensure the best possible use of available skills and resources. In 1999, The AIDS Bureau funded the Community-Linked Evaluation AIDS Resource Unit (CLEAR Unit) to work collaboratively with AIDS service organizations to promote evaluation and research. Other researchers, (Sanstad, Stall, Goldstein, Everett and Brousseau, 1999) have described this arrangement as a collaborative community research consortium whose focus is to develop a model of community collaborative research to bring the skills of science to the service of HIV prevention and support services, and the knowledge of service providers into the domain of research. These partnerships promote productive relationships between academia and community organizations.

The Information Management Project of the CLEAR Unit collaborated and offered support to AIDS service organizations (ASOs) as they developed methods to collect and manage data. This CLEAR Unit Information Management Project was developed to support and empower community organizations to develop information technologies for the purpose of using information to inform decisions. This was accomplished in three succinct ways:

First, one of the biggest challenges for community groups is gathering information. Thus the CLEAR Unit took the initiative in helping groups learn about gathering their own data and using this relevant data to help to make decisions for

service. Through the Information Management Project, the CLEAR Unit became an intermediary between the technology and the community groups.   This project helped provide ASOs with their own readily available data and data management technology "know- how". This information will help develop local programs and to advocate change where needed.   This CLEAR Project worked in partnership with organizations to help them collect raw data, help put the data into context and to link the data to information that may be helpful in changing policy.   One key component of this link was the attempt to empower the ASOs through training or consultation to turn data into information.

Secondly, with the advent of large databases now accessible to researchers and organizations, such as the Statistics Canada and the future Central Research Database at OHTN, much information will be available in raw form. According to Sawicki and Craig, 1996, this has been called the democratization of data, and in the United States, institutional or university partners have been encouraged to collaboratively work with community organizations so they can make full use of this information availability. It is understood that some organizations will need assistance in interpreting and understanding this information. Eventually many will become self sufficient in using information technology and using databases such as these to direct their services.   With the advent of the new changes in technology, such as more affordable desktop computers with large storage devices, community groups may make significant use of electronic information and large databases. These groups can then afford the cost of entry into the world of sophisticated data. However this also means less accessibility to information on paper and much data may become inaccessible to those without the technical sophistication to access it.   At present in Ontario, it is thought that the ASO's capabilities to take

advantage of new raw data resources is limited as not all community groups can turn data into information, information into knowledge, and knowledge into policy. They need support and assistance with technical skills to read data and then more skills to interpret that data into something meaningful for the organization. The CLEAR Unit Information Management Group attended Statistics Canada meetings on using Stats Can databases, and OHTN meetings of the HIIP Advisory Committee that is overseeing the development of the Central Research Database for HIV affected persons in Ontario. We are examining the possible use of this data by the ASOs in Ontario, for planning supportive care.

Third, the AIDS Bureau streamlined their reporting system, by gathering statistics from ASOs via electronic formats. The CLEAR Unit assisted with the development of templates for use by ASOs to report statistics to the MOHLTC. In addition the CLEAR Unit assisted with workshops explaining the use of these templates. In addition, assistance with managing and interpreting data from ASOs was offered to representatives of the AIDS Bureau. Future analysis and report generation is planned.

PURPOSE

Thus the **purpose** of this CLEAR Unit Macro Information Management Project was to assist and support community groups in their use of information and its technology.

METHODOLOGY

Design

This is a descriptive study, identifying some database needs, technology use and available human resources at some ASOs. It will also identify their requirements for research data gathering and reporting of statistics to the Ministry.

Objectives

To offer assistance and support based on the assessment, with help with the development of databases and electronic templates for understanding their own activities and reporting these to the MOHLTC and others.

Setting

The CLEAR Unit at McMaster University in Hamilton carried out the study. Members of the Unit visited ASOs identified by the Steering Committee or CLEAR Unit researchers. Assessments and visits were made at ASOs in Ontario and meetings were held at the AIDS Bureau with representatives to assist with electronic transmission of reports via email. There were workshops with the MOHLTC and all Ontario ASOs.

Sample

Thirteen ASOs that were participating in CLEAR Unit Evaluation projects were chosen to have assessment visits from the Information Management Group of CLEAR. In 2002, other ASOs that attended the workshops on MOHLTC reporting forms were

offered pre tested templates and databases. In addition there were meetings with the CLEAR Unit and the staff at the MOHLTC AIDS Bureau.

Research Objectives

To learn about the ASO information capacity; and assess the ability of ASOs to use newly developed information databases and templates?

Specific Research Questions

1. What are the present computer, database and resource capacities of 13 ASOs involved in research projects with the CLEAR Unit?

2. Which software programs are most beneficial in helping ASOs gather data?

3. What are some ways to gather data for MOHLTC reports?

4. What information, gathered in these databases, will be helpful for the CLEAR Unit projects?

5. What other information databases will be needed for CLEAR Unit projects?

6. What other large databases are available to ASOs and the CLEAR Unit? What research questions can be answered from these databases?

7. What electronic reports are needed by MOHLTC (AIDS Bureau)?

8. What is the best way to collect data for ACAP reports?

Activities

The Information Management Project included three main activities: 1) Collaborative work with ASOs on data management, 2) examination of large research

databases for potential use for AIDS Bureau and/or Service organizations, and 3) collaboration activities with the MOHLTC in developing electronic forms and sophisticated analysis techniques for ASO statistics and information.

RESULTS

1)   Collaborative Partnership With ASOs

This collaborative partnership with ASOs included four phases: A) assessment; B) implementation; C) support and review; and D) dissemination.

A)   <u>Assessment Phase: 2000, 2001</u>

There is no known documentation on the information systems in ASOs and affiliated organizations. Each ASO has different computer hardware and software and different abilities and resources for developing and maintaining information databases about their organization and services, as well as manipulating raw data from other sources. Thus the CLEAR Unit, Information Management Project, assessed the present state of technology and personal resources in 13 ASOs for gathering data and managing this data. This included data needed for program and administrative purposes as well as client databases. Of the thirteen ASOs visited in 2000 and 2001, all were interested in developing expertise in data collection and management, however few had complete data collection systems already in use. Only one Toronto organization had most activities computerized. All others had either partial databases or none at all. All had the hardware and software needed for email, fax and computer requirements for gathering data and using templates for the MOHLTC reporting forms. All had Microsoft with EXCEL and

ACCESS 97. Many did not have staff fluent in computer technology, however many were recruiting persons for these activities or had volunteers that were lending support. The CLEAR Unit found that different ASOs were using different methods for entering and maintaining data and producing records. This assessment also provided information on the ability of ASOs to gather data and measure outcomes for evaluations of other CLEAR Unit projects. It was noted that most ASOs would have trouble collecting data on their own and would require the help for data collection and management by the CLEAR Unit.

B)   Implementation Phase: 2001

In order to assist the Ministry Of Health and Long Term Care (MOHLTC) and the ASOs, the CLEAR Unit helped develop databases for reporting purposes. Computer science students at McMaster as well as staff and consultants of the CLEAR Unit developed templates and databases. These were offered to ASOs to pretest. These databases assisted with managing data in their ASO or reporting data to the MOHLTC on electronic forms. Present databases were enhanced where possible. In all eleven templates or databases were developed.

C)   Support and Review Phase: 2001, 2002

The CLEAR Unit staff and consultants supported ASOs as they tried these new databases and new electronic reports. The CLEAR Unit helped develop new skills, through visits and workshops.

D) <u>Dissemination Phase: 2002</u>

CLEAR Unit investigators met with other ASO staff to suggest how these developed templates and databases would help with data management and interpretation, as well as reporting to the MOHLTC. Dissemination, transference and translation activities were encouraged through workshops, emails, newsletters and conferences.

2) Large Databases

The OHTN is planning a Central Research Database, for persons infected with HIV/AIDS. This database, which gathers data from primary care physicians for clients agreeing to participate, will link with other databases from labs, hospitals (CIHI), CCAC's etc. Potential inclusions for this database include data on use of health and social services and client quality of life information gathered from the clients themselves. The CLEAR Unit is interested in the development of this database. Specifically of interest will be identifying the usefulness of this database for ASOs and the CLEAR Unit, when it is completed. Completion of the HIIP database is planned for the end of 2002. If this database collects information on use of ASO services by these clients and reasons for their use, this will be important for future evaluation activities by the CLEAR Unit and the ASOs. Other databases such as Statistics Canada have been examined and as yet it is not thought that they will provide valuable information for these community organizations. The CLEAR Unit will continue to monitor these databases possibilities
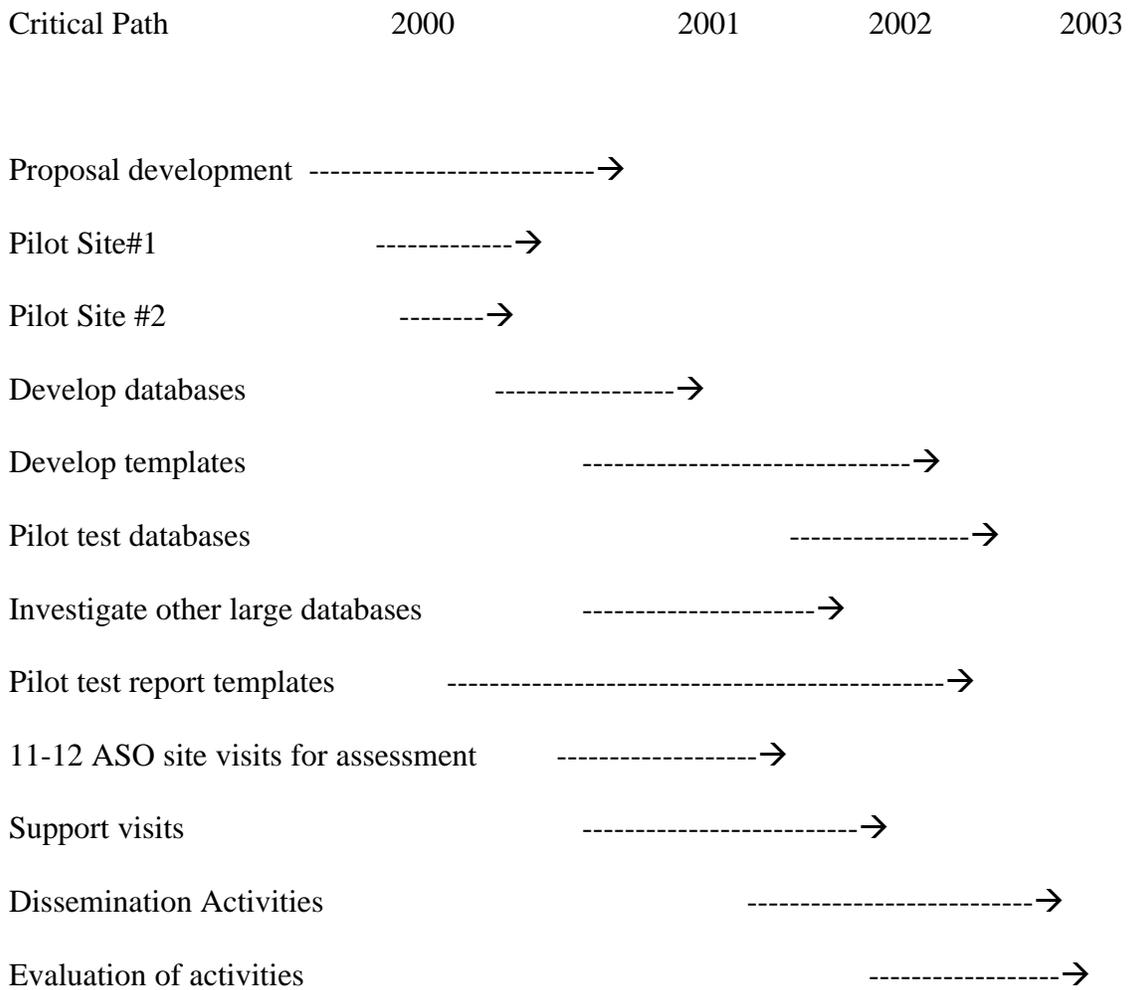
3)   MOHLTC Reports

The CLEAR Unit assisted with developing the template for ASO data entry, analysis procedures and interpretation of data from MOHLTC quarterly reports sent in by ASOs.   Any data seen by the CLEAR Unit was reported by an anonymous code, so sites are not identified. The CLEAR Unit has pre-tested analysis of data and is awaiting the yearly data from 2001-2002.

Specifically the CLEAR Unit assisted and supported some ASOs to: a) gather data or obtain data from appropriate sources; b) enhance their skill with using information and interpreting data analysis to affect policy and practice; c) gain confidence in the results and themselves, as products of information technology were produced by the community organizations themselves along with the CLEAR Unit; and d) sustain these efforts for the future. In addition the CLEAR Unit will help evaluate the effectiveness of this collaborative project.

TIME FRAME FOR ACTIVITIES

The activities started in April 1, 2000 and will continue indefinitely as required by the MOHLTC, AIDS Bureau.

Critical Path	2000	2001	2002	2003

Proposal development --------------------------→

Pilot Site#1   ------------→

Pilot Site #2   --------→

Develop databases   -----------------→

Develop templates   ------------------------------→

Pilot test databases   -----------------→

Investigate other large databases   ----------------------→

Pilot test report templates   --→

11-12 ASO site visits for assessment   -------------------→

Support visits   --------------------------→

Dissemination Activities   ---------------------------→

Evaluation of activities   ------------------→

COMPLETED ACTIVITIES

1. Assessed or visited 13 ASOs for fact-finding in order to determine a) types of information gathered, b) databases that are used, and c) resources that are available in the ASOs. The OAN is continuing this function in 2002 (Appendices B and E).

2. Designed strategies for helping ASOs develop or use present databases for gathering information for MOHLTC recording activities, as well as for other "in-house" reports (Appendices A and D).

3. Visited 13 ASOs (identified by the CLEAR Unit) to assist with self-identified learning needs related to their information gathering systems. Eleven databases or templates were completed. Computer science students did two databases as special projects in their final undergraduate year at McMaster University. Jacqueline Roberts and Maria Wong supervised these students (Appendix C).

4. Determined data gathering requirements of the MOHLTC. Assisted with techniques for data management and analysis of anonymous data (Appendix B).

5. Identified and learned about other databases that may have information related to ASO services such as the Central Research Database of the OHTN, and Statistics Canada Databases.

6. Developed useful (for CLEAR, ASO, MOHLTC) information databases that help produce statistics for the MOHTLC reports and "in-house" reports of the organization (Appendix B).

7. Supported ASO personnel while using databases in the ASOs identified by the CLEAR Unit (Appendix B).

8. Pre tested the MOHTLC 2000-2001 form for its usefulness and acceptability to ASOs and the MOHLTC (Appendix A).

9. Assisted ASOs where required for the use of the MOHLTC quarterly report form for 2001 and 2002. These templates are being used by all ASOs in Ontario (Appendix A).

10. Met with ACAP and ASOs on the possible design of a form for reporting of their activities to ACAP.

11. Commenced dissemination activities for the 55 ASOs related to the 11 databases and templates developed (Appendices C and F).

12. Summarized feedback on the helpfulness and usefulness of the Information Management Activities. Those ASOs that pre tested databases or activities were asked for written feedback using a questionnaire that asked for degree of helpfulness of CLEAR Unit staff and the usefulness of the database or template for their organization (Appendix C).

CLEAR STAFF RESOURCES

Personnel:

Project Investigators**:** (Jacqueline Roberts, Gina Browne, Greg Robinson)

Develop project proposal

Oversee project completion

Evaluate Project

Examine and assess large databases

Liaise with MOHLTC AIDS Bureau

Write reports

Computer Hardware and Software Consultant: (Ted Bailey)

Carry out the assessment of ASO information systems

Train ASO personnel to use information databases

Assist with Database and Template construction

Test Database and Templates

Design User Manuals

Data Analyst**:** (Maria Wong)

      Develop databases using ACCESS

      Software support

      Analyze MOHLTC quarterly reports

      Assist with design of user manuals

Secretarial Support Staff

      Typing reports

McMaster University Computer Sciences Students

      Develop databases on ACCESS

REFERENCES

Sanstad, K. Stall R. Goldstein, E. Everett, W. Brousseau, R . (1999) Collaborative Community Research Consortium: A Model for HIV Prevention. Health Education and Behavior; 26(2): 171-184

Sawicki, D., Craig, W. (1996) The democratization of data: Bridging the gap for Community Groups. APA Journal. Autumn: 512-523
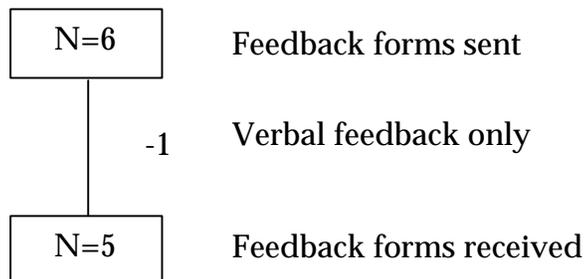
INFORMATION MANAGEMENT MACRO

EVALUATION OF DATABASES

Evaluation:

Six feedback letters were sent to ASOs who received databases or templates and agreed to pretest them for the CLEAR Unit. These forms asked the agency; how we might help them with further refinements; if the databases or templates were useful; and if they found our assistance helpful.

Information Management

Flow Chart

```
┌─────────┐
│   N=6   │      Feedback forms sent
└────┬────┘
     │        -1   Verbal feedback only
┌────┴────┐
│   N=5   │      Feedback forms received
└─────────┘
```

March, 2002:

Five forms were returned, indicating that these databases and templates (#2, 3, 4, 9, 10) were useful and helpful. The form for Package #1 was not returned. Verbal feedback indicated that the agency wished to redesign their method of gathering information of the five forms returned, four (100%) indicated the database or template

was useful. One did not answer the question. The mean score for the helpfulness of the

CLEAR Unit was 4.6 out of 5, indicating the staff were extremely helpful.

ASOs indicated these templates or databases were well received.

	N	%
Database useful	4/4	100
	Mean	**SD**
CLEAR Unit helpful (1-5)	4.6	(0.5)