Hepatitis C Information Project Program of the Okanagan (HIPPO)

Evaluation Report 2001/2002

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1 Background

This report represents an evaluation of work undertaken by the HIPPO project during the fiscal year 2001/2002. While the project activities will be assessed within this report, this report is intended to complement or extend upon the comprehensive project status information contained in the HIPPO project's April 30, 2002 update report. We do not wish to duplicate the information contained within previously submitted reports.

During the past year, the HIPPO project has been guided by an evaluation framework last revised in March 2001. Working with HIPPO representatives we developed the evaluation framework and selected and prioritised the goals and activities included in the framework based on the following five principles:

1) Informational return on resource investment,
2) Feasibility of undertaking a reasonably rigorous evaluation of an activity,
3) Relevance to the community,
4) Interest to the investigating agency and agency clientele, and,
5) (As directed by Health Canada) relevance of the activity to the principles outlined in the document, "Hepatitis C Prevention, Support and Research Program: Evaluation Framework (Health Canada, August 14, 2000)."

We still believe these five principles are useful organizing criteria. Previously, we have suggested only relatively minor iterative changes be made to the evaluation framework, in response to improved information about how concepts developed in the board room actually perform in the field, or because a population of interest have not engaged with project activities as had been anticipated. This year, however, we feel more fundamental changes in the implementation of the HIPPO project should be considered. These changes amount to selecting a few key activities to focus efforts on, and doing those activities very well while building capacity within the project staff to improve their effectiveness at moving the project forward. While we recommend that a fundamental refocusing of the project objectives be seriously considered, this is a decision for the project director and the project advisory board. Should the decision be made to re-focus the project efforts, this will obviously necessitate redevelopment of the project evaluation framework. The nature of the reformulation will depend, of course, on which activities are preserved and the priorities given to them. The present evaluation framework cannot be redeveloped until decisions regarding the foci of the HIPPO project are made.

Aside from providing an overview of project progress with respect to the established evaluation framework, this report will focus on identifying the challenges encountered during the last year and making recommendations to address these challenges. While this emphasis may be a departure from the expected enumeration and analysis of the outputs and outcomes of various project activities, the current status of the project, the challenges it is facing, and the short time remaining in the project all combine to force us to take a systemic approach to the evaluation. This report represents an evaluation of the HIPPO project in the broad sense, using stated goals, objectives, and an evaluation framework to help situate a lower level discussion of how to maximize project success in the next fiscal year. Our recommendations are general in nature and are not specific to any particular

course of action that may be taken with respect to possible changes in project focus or priorities.

This report will briefly review the project objectives, the development of the evaluation framework, and the status of project activities, moving to a discussion of project challenges and successes and finishing with a number of recommendations for fiscal year 2002/03.

2 Project objectives

The overall goal of the project is to educate both the general population and individual infected and affected by hepatitis C with the information they require to respond appropriately to the disease. The more comprehensive goals of the project are to provide Okanagan residents with a better understanding and appreciation of the nature and effects of hepatitis C, engendering greater sensitivity to and support for persons affected by the disease, and to improve the quality of life for persons living with hepatitis C by providing them with knowledge of the disease, and information and skills on how to access programs and services available in the community.

2.1 Specific project goals and activities

The priority ranking for each activity, current as of mid-May 2002, is shown in Table 2. The activities shown in the Table above correspond to the evaluation discussed in the April 30, 2002 update report. Also refer to the update report for further information regarding each activity's intended and realized outcomes.

Tying for top priority are training speakers for, and conducting, informational talks, or "speaks." Providing these speaks are well rehearsed they are a good way of communicating hepatitis C information to a group of people in a face-to-face setting. HIPPO would like to maintain their success with this approach, and in order to do so, they need to train more speakers to conduct the talks.

With the surveys of community-based organizations (CBOs) now complete (or nearly complete), follow-up should be done as quickly as possible to further specify opportunities for developing hepatitis C capacity among those agencies, and to complete another activity as quickly as possible, to achieve another "quick win" by releasing the findings of the CBO survey and follow-up. This could potentially be the subject of a media release, thereby producing another output for public information dissemination (goal 3, activity 1).

A number of activities are left unranked. These are left unranked at present because it is not clear how their ranking would be adjusted should a decision be made to refocus the project goals and activities.

Table 1: Most recent project goals, activities, and their priority ranking.

Rank / Status	Activity
complete	Activity 1: **(of goal 1)** Establish Advisory Committee
complete	Activity 2: **(of goal 1)** Survey of Physicians in the region (approx. 558 in Sept. 2000 and 397 in Sept 2001) Physicians identified in ARC database
Near complete, data entered	Activity 3: **(of goal 1)** Survey: 1) Community-Based Social Service agencies in the region 2) Administration Officials of the following Provincial Ministries:
2	Activity 1: **(of goal 2)** Interviews with representatives of Community Based Groups that indicated an interest in developing Hepatitis C capacity on Community Group Survey (see Goal 1, Objective1)
3	Activity 1: **(of goal 3)** Generate and distribute information to the public regarding prevention, care treatment and support for Hepatitis C
4	Activity 1: **(of goal 4)** Needs assessment (Consultation with individuals infected with Hepatitis C and/or their caregivers to determine skills and resources needed to support self-advocacy)
unranked	Activity 2: **(of goal 4)** Work with community based programs so that they can provide tools necessary to help develop self-advocacy skills for those living with Hepatitis C and/or Hepatitis C caregivers
unranked	Activity 1: **(of goal 5)** Peer Counselling Training (PCT) Program based on very successful program provided by the British Columbia Persons with AIDS Society
unranked	Activity 2: **(of goal 5)** Counselling sessions
unranked	Activity 3: **(of goal 5)** Train the Trainer (TTT) – develop a TTT Program from the Peer counsellor Training Program
unranked	Activity 1: **(of goal 6)** Training the Community Based Agencies who have committed to provide the delivery of services and programs in each area (identified through Goal 1, Goal 2)
1	Activity 1: **(of goal 7)** Using the current model of the ARC Speakers Bureau, train volunteers to deliver educational sessions to the identified community groups, social service agencies and governmental agencies
1	Activity 2: **(of goal 7)** Doing speaks

Table 2 provides an overview of the current status of the various activities in the evaluation framework. With respect to the survey work completed as part of goal one activities, a number of positive outcomes were realized in spite of the low response rates achieved that were generally achieved. For the physician survey in particular, the survey produced valuable information to assist HIPPO with client health care referrals, such as which physicians are willing or not willing to treat hepatitis C-positive patients, would accept new patients, currently have hepatitis C patients in their practice, and who might be prepared to offer assistance with future information collection or distribution. One weak point with the survey information, aside from the fact that HIPPO received no information from more than two-thirds of sampled physicians, is that the physician-specific information will date relatively quickly—this may be especially true for wait lists and whether practices are open or closed. Discussion of the outcomes of the Ministry and CBO surveys will have to await final data entry and analysis of the collected data. At the present time, only 22 needs assessment surveys have been returned; the survey strategy being used needs to be revisited to improve the rate of returns, and the potential for analysis of those data once a large sample of completed questionnaires is in hand also needs further consideration. Only one media release has been issued so far, and a local paper picked up the story. Clearly, opportunities exist to leverage information held by or

being created by the HIPPO project to produce more media releases and raise the profile of the HIPPO project specifically and hepatitis C in general.

Evaluation forms for informational "speaks" are the only other activity for which output data has been regularly documented. The project coordinator has a database containing responses to two questions from 408 participant evaluation forms. Analysis of these data may be of some interest, but the advisory committee may want to consider revising the evaluation forms to provide more informative quantitative and qualitative information.

Table 2: Summary of status for each activity in evaluation framework

Activity	**Framework ref. goal & activity**	**Performance**
Advisory Committee	G1,A1	Established, regular meetings held and minutes taken
Physician Survey	G1,A2	1st attempt: 558 physicians sampled (Sampling frame construction criteria not documented) 25 surveys returned (4.5%) No efforts made to contact non-respondents or otherwise improve response rate. 2nd attempt: 397 physicians surveyed (Sampling frame construction criteria not documented, some effort made to remove non-practicing physicians from sample) 126 surveys returned (31.7%) One follow-up phone calls made to all non-respondents (two calls made to most) Additional responses received from follow-up effort not documented.
CBO & Gov't agency survey	G1,A3	CBOs: 68 agencies sampled. (Sampling frame constructed using a year 2000 directory of regional CBOs. Efforts made to determine specific addressee at each sampled agency 34 surveys returned (50%) Gov't: 12 Ministry offices sampled, 11 questionnaires returned completed
Follow-up interviews with CBOs	G2,A1	No action yet taken
Generate and distribute hepatitis C information to the public (media promotion)	G3,A1	One media release issued. One article printed in Kelowna Capital News Feb 08, 2002.
Hepatitis C+ needs assessment	G4,A1	Surveys distributed via third-party contact (physician offices, health units). HIPPO blinded to identities of prospective survey participants. 22 completed surveys received.
Training CBOs to assist Hepatitis C+ in self-advocacy	G4,A2	No action yet taken
Peer Counselling Training (PCT)	G5,A1	No action yet taken
Peer Counselling sessions	G5,A2	No action yet taken
Peer Counseling Train the Trainer (TTT)	G5,A3	No action yet taken
Training CBOs how to deliver services to Hepatitis C+	G6,A1	No action yet taken
Train volunteers to do hepatitis C speaks	G7,A1	No volunteers trained since January 2001. Net loss of four or five speakers from January 2001 to present.
Undertake hepatitis C speaks	G7,A2	See list of completed speaks in 2001-2002 update report. Evaluation forms for 408 cases entered into the database.

3 HIPPO evaluation framework

This report examines the HIPPO project's progress against the goals set out in the evaluation framework as of April 01, 2001. The evaluation framework was developed to identify a set of indicators which could be used to identify and measure project progress, successes, and challenges. A copy of the project evaluation framework is attached as an Appendix to this report.

The first evaluation framework for the HIPPO project was developed two years ago, shortly after the project was initiated. The framework articulates a logic model connecting project goals to project activities, outputs, and outcomes. Indicators, and the mechanisms through which data needed for the indicators were to be acquired, were defined for outputs and short, medium, and long-term outcomes as appropriate. The framework has undergone a number of revisions since the start of the project, but these changes have been incremental in nature, with minor changes being made in response to specific challenges. The current framework consists of 13 activities distributed across seven project goals.

The project started with an ambitious list of goals. Lack of progress against goals in year one did not force an adjustment of these goals as it was felt they were still achievable of time remaining. A second year of slower than anticipate progress now places the project in the position of being in the last year of funding with a number of goals that have yet to have seen any activity and which will require a very large commitment of resources to execute successfully.

Typically, we approach a project evaluation by first enumerating those activities within the framework that have been undertaken during the period of interest, and then examining how successful the outputs from the activities have been in achieving their outcomes of interest. A number of factors (described later in this report) have combined to impair the project's progress over the last fiscal year. Additionally, documentation of project activities has not been done in an organized, routine, or consistent manner. This makes program evaluation difficult.

At the present time, there is very little information available to analyse for this evaluation report. Univariate results from the one completed activity (the physician's survey) have been summarized in an earlier document and will not be reported here. Other documentary information summarizing outputs from the various activities staff have been engaged in over the last year have not been collected and recorded consistently, but we have compiled a general summary of activity outputs which are shown in Table 2 above. Without data available to analyse, our evaluation will shift from data analysis to a focus on identification of some of the factors which have contributed to HIPPO's slower than anticipated progress, documentation gaps, and other challenges, and offer a number of recommendations to help address these problems.

4 Challenges

The HIPPO project has encountered a number of internal and external challenges in the past fiscal year. Internal challenges representing the greatest impacts for the HIPPO project include staffing difficulties, inefficient project management, and highly ambitious—perhaps over-ambitious, given the other internal challenges—goals for the project as a whole. External challenges included the typical difficulties obtaining an acceptable response rate for mail-out surveys to physicians and community-based organizations, difficulty obtaining buy-in from a needle exchange, difficulties encountered in attempts to establish partnerships with other organizations, and continual distracting pressures to undertake an active hepatitis C advocacy role particularly in light of the threat of and realization of substantial budget reductions for many health and social services provided by the provincial government. This report will touch briefly on each of these challenges.

4.1 Internal challenges

4.1.1 Staffing issues

There have been multiple changes in staffing for the project coordinator position over the last year. Merv McLeod, the individual initially hired as the coordinator at the beginning of the project, took an extended medical leave beginning in April 2001. He returned in mid-September but left again for December, returning January 2002. During his absence, two other individuals took on the coordination role in succession. Mr. McLeod remains in the position at the present time. Such staffing discontinuity in a coordinator position would present a challenge for any project, but it has created serious difficulties for HIPPO given the developmental nature of the coordinator's work, and the varied nature of the multiple activities in which the project is actively engaged. This situation presents a huge learning curve for staff taking over the position; furthermore, the nature of the staff transitions did not permit project-specific information to be transferred effectively from the departing to the arriving staff member. As a result, information regarding project status, priorities, time sensitive activities underway, community communications, and documentation were not transferred effectively, creating serious negative impacts for the project.

While it may not always be possible to plan and manage staff transitions to ensure a smooth transfer of knowledge from one staff member to another, the enumeration of the scope of the difficulties presented by such staff changes should underscore the seriousness and longevity of negative effects of staff changes, and it may be appropriate to use these times to re-assess existing and planned project activities to ensure that expectations for meeting goals and their deadlines are still realistic, and perhaps to re-orient (if necessary) the activities of the project to appropriately reflect the skills, knowledge, and interests of a new staff member.

4.1.2 Project management

The management and documentation of the various activities undertaken within the HIPPO project has not been as structured, routine, and well managed as it could have been. Aside from issues with the prioritization, planning, documentation, and work flow management skills of the project staff, the difficulties in addressing this challenge are compounded by the staffing discontinuity just described. Among activities identified as high priority during last fiscal year, the project faced general project management and documentation challenges including problems with activity planning and implementation, monitoring of activity progress, documentation of processes, collection and recording of structured and routine information identified in evaluation framework for use in measurement of evaluation criteria, and application of sustained and appropriately focussed effort on active activities. Keeping the focus of work activities in line with project priorities has, at times, been a challenge. Given that the HIPPO project began with a fairly ambitious set of goals requiring active and simultaneous engagement in multiple project activities, such project management difficulties resulted in slower than anticipated progress and the application of more resources to problems than would have been required with better planning and implementation.

4.1.3 Ambitiousness of project goals

The HIPPO project presented an ambitious list of goals as part of its original project proposal. For the most part, these objectives have remained as part of the project work plan and evaluation framework since the project's inception. The ambitiousness of these goals and objectives has itself presented a challenge for the project, particularly in light of the staffing discontinuity experienced in the past year coupled with difficulties among the coordinators with focus on and maintenance of work activities in line with project priorities. With no formally recognized adjustments being made to the work plan as a result of the internal and external challenges, there seemed to be a sense among the project staff that they were expected to "do everything" in spite of tightening time lines and successively increasing confusion regarding the status of progress being made toward specific objectives.

4.2 External challenges

4.2.1 Primary data collection

The HIPPO project encountered a number of external challenges related to primary data collection. One of the main challenges faced in data collection activities in the last year was the difficulty of getting participation from physicians in the region. Even with a carefully validated sample of physicians for the second attempt at the physician survey, and at least one (and typically two) follow-up phone calls to each sampled physician's office, the survey response rate was still barely 30 percent. HIPPO's difficulty in obtaining and maintaining the interest and participation of physicians is further underscored by the nearly non-existent participation of physicians as third-party contacts for HIPPO's needs assessment survey: only a handful of surveys have been received from

physician third party contacts in spite of surveys being sent to 43 physicians with hepatitis C patients.

It was a challenge to get survey responses from community-based organizations as well. In spite of mailing each survey to a specific individuals within each organization and two follow-up phone calls to each non-responding individual, the community-based organization survey has, at the time of writing, only a 50% response rate.

Access to the population of interest has also proven to be a challenge. Initially HIPPO had planned to survey the active injection drug user population using the Kelowna Needle Exchange as a point of contact. HIPPO was unable to negotiate direct access to clients at the needle exchange, thus necessitating a shift in the population of interest from active injection drug users to drug users in recovery[1].

4.2.2 Difficulty establishing partnerships with other organizations

Establishing workable partnerships with other organization can often be difficult. There have been a few examples of such challenges in the HIPPO project, and those that have directly affected the project's ability to obtain survey data have been the most serious over the last year. The barrier presented at the Kelowna Needle Exchange forced the project to alter its population interest from active to recovering injection drug users, since access to active drug users at the needle exchange was denied. Fortunately, none of the other difficulties encountered establishing partnerships required a change in population of interest. The project was unable to obtain buy-in from any of a number of key physicians in the area to co-sign the introductory and promotion letter that accompanied the physician surveys, and has so far been unsuccessful establishing a meaningful partnership with Dr. Chai, who has perhaps the largest hepatitis C patient list in the Okanagan. Finally, the project was unable to establish a workable partnership with the hepatitis C support group in Princeton, the details of which have been included as part of the April 30, 2002 project update report.

4.2.3 Pressure to take on an active advocacy role

The last external challenge we will describe here is the pressure HIPPO has faced—and more concerning, the pressure we anticipate it will face in the future—for it to take on an active advocacy role for people affected by hepatitis C. The recommendations listed under Section 3.10 in the April 30, 2002 project update also appear to have a general leaning toward advocacy. This issue is discussed in more detail in Section 6.5.

[1] HIPPO has recently worked out an agreement with the Kelowna Needle Exchange which now permits them to distribute needs assessment surveys to needle exchange clients, whereby the street nurses act as third-party contacts for survey distribution.

5 Successes

5.1 Incubation of support groups

The HIPPO project encountered a fundamental difficulty when trying to engage in project activities which involved connecting with people affected with hepatitis C in the Okanagan: there was no feasible way in which to connect with affected individuals. As an innovative solution to this problem, the additional activity of *creating* the groups to be used to contact people was added to the HIPPO project plan. HIPPO has since taken a formative role in establishing and fostering three hepatitis C support groups in the Okanagan.

5.2 Sustainability of HIPPO efforts

Despite the slow progress in meeting project objectives, HIPPO has already generated a number of outcomes which may have wide-ranging and long-lasting positive impacts for hepatitis C in the Okanagan. Helping set the hepatitis C support groups in motion holds the potential for a very constructive and sustainable project outcome. Even with a 30 percent response rate, results from the physician survey can be used to help connect hepatitis C-positive individuals with knowledgeable physicians who have openings in their practice. While the list itself would need regular updating in order to keep it current, the longer-term clinical outcomes that could be anticipated as a result of having better case management for hepatitis C-positive individuals should extend beyond the termination of the HIPPO project.

5.3 Identifying and using well-placed individuals

The project has benefited greatly from the contributions of a number of generous, competent, and well-placed individuals. In addition to the extremely useful input received from the advisory committee, the project was able to identify and use an individual in the BC government who was able to identify specific individuals in government offices in the Okanagan that worked with clients on disability issues. In addition, HIPPO has been able to identify and utilize a number of influential stakeholders who have been able to facilitate the advancement and promotion of some project activities to specific groups of interest. In addition, there has been some success in identifying and obtaining buy-in from gate keepers at points of interest such as health clinics and, more recently, needle exchanges.

6 Recommendations for fiscal year 2002/03

The general thrust of our recommendations is for the HIPPO project consider carefully what can be realistically accomplished in the time remaining, and to manage project activities more effectively. We feel that it is unrealistic, given the challenges encountered during the first two years of the project, to expect all the objectives set out in the original funding proposal to be met by the end of the 2002/03 fiscal year. It is in the interest of all parties that the activities undertaken by the HIPPO project are done well and represent a positive contribution to the community. We feel it is preferable to complete the project with select objectives met and done well, than achieving poorer outcomes across a broader range of activities.

There are a number of ways in which project success can be maximized during the next fiscal year. As suggested above, one option that should warrant serious consideration is dropping one or more goal/activity sets from the work plan, thereby freeing resources to focus on those activities considered to be most central, valuable, or feasible. This would require refocusing of project activities within the context of a concomitant narrowing of project objectives; this in turn should be supported by a realignment of the project's overall strategic vision. Given the challenges created for HIPPO's constituency by the province's budget reductions in health and social services, we anticipate that individuals associated with the HIPPO project—and potentially the project itself—will be facing increasing pressures to directly advocate on behalf of persons affected by hepatitis C. This is currently not part of HIPPO's mandate, and how those responsible for guiding and supporting the project determine the response to this challenge will have a direct impact on how well HIPPO is able to fulfill its objectives. We also make some suggestions that have the potential to substantially improve the effectiveness of project management, particularly with respect to data collection, documentation, and data set access and integration. We also recommend that HIPPO and Health Canada come to a formal agreement regarding the role the HIPPO project is to play in fostering the development of new hepatitis C support groups in the Okanagan region. A number of specific recommendations for the fiscal year 2002/03 are described below.

6.1 Update the project's strategic vision

Building on the experience gained through two years' activity in the field, we recommend that the project director and advisory committee revisit and update the strategic vision for hepatitis C education initiatives in the Okanagan region in general and the HIPPO project in particular, with a focus on an initiative's core values, key activities, partnerships and exploration of options for future directions and their potential pay-offs. The ability to leverage the range of HIPPO achievements (i.e., capacity building, community partnerships, and goal-oriented outcomes of project activities) for future health promotion and health and social policy applications, and an assessment of available funding sources to support sustained future efforts building on work done through the HIPPO project should be taken into account when considering the larger strategic vision.

6.2 Reassess project goals

We recommend that all goals in the evaluation framework be reassessed, and that project goals be narrowed down to include only those goals rated highest in terms of importance to the overall project and the feasibility of achieving the goal with the time and resources available. The selected goals should also be most closely aligned with the project strategic vision and the selection must be agreeable to the HIPPO director, the project advisory committee, and Health Canada.

6.3 Narrow focus of activities

To provide further focus to the activities undertaken through the HIPPO project, we recommend that the project director and advisory committee consider eliminating some

activities from the project work plan to permit resources to be committed to those activities considered most important, and most feasible given the limited time and resources available for completion of the project. For example, no significant progress has been made on any of the activities grouped as part of goal five (peer counselling training, undertaking peer counselling, development of a train-the-trainer program for peer counsellors). It is likely not realistic to expect that all three of these activities can be initiated and completed next year. The second and third activities are dependent on successful engagement in each antecedent activity. Even if program development went extremely smoothly, it is unlikely that a sufficient number of individuals could be trained and obtain sufficient experience to be in a position to train a significant number of peer-trained counsellors. Efforts should be focussed on those activities in which a high level of success can be reasonably anticipated.

6.4 Work to obtain some "quick wins"

To date, work on the HIPPO project has been developmental and procedural in nature: committees and partnerships have been developed, survey instruments designed and data collection undertaken. Staffing issues and other internal challenges slowed progress toward the project goals. There have been few project outcomes that one can point to as a product resulting from project activities. We recommend that the project work to produce some concrete products or measurable results as soon as possible. This may mean shifting activity priorities and resource allocation to support selected activities that could be completed quickly and successful. In addition to producing outcomes which can be promoted to partners and the larger community, such products may prove useful during the impending funding proposal process. An example of a quick win might be the rapid collection, analysis, and reporting of interim results from client needs assessment surveys completed by injection drug users visiting needle exchanges in the region.

6.5 Consider carefully HIPPO's role in hepatitis C advocacy

The project must weigh the potential benefits and risks of responding to increasing pressures to take active hepatitis C advocacy role. The current mandate of the project is to educate about hepatitis C and train individuals and organizations in effective hepatitis C advocacy without providing advocacy itself. The organizational situation of HIPPO within the ARC, may provide an opportunity for HIPPO to remain true to its mandate while HIPPO and ARC combined may be able to provide infrastructure to develop some capacity under the ARC umbrella to provide direct hepatitis C advocacy without distracting the efforts of the HIPPO project; in fact, such an initiative could be configured to be entirely complementary to—and perform symbiotically with—both HIPPO and ARC. Given that the current political climate and budget issues facing health and social programs in BC can be expected to persist for some time, bringing with it pressures for staff associated with the HIPPO project to advocate on hepatitis C issues, the project director, advisory committee, and appropriate funding agency representatives should discuss now what role would be appropriate for HIPPO now and in the future, particularly with respect to direct advocacy activities.

6.6 Clarify HIPPO's role as hepatitis C support group incubator

While we recognize that HIPPO has benefitted assist the establishment and development of hepatitis C support groups in the Okanagan region, and that HIPPO has obtained a measure of success as a facilitator or incubator for fledgling support groups, such a role is significantly pushing the boundaries of HIPPO's mandate as a provider of hepatitis C information. The adoption of the support group incubator role flows directly out of difficulties encountered in identifying groups of individuals affected by hepatitis C, and the innovative solution to develop the infrastructure to permit contact with this population of interest was developed. There are clear indications that HIPPO is having success fostering these groups, and the development of these groups themselves should be friendly to Health Canada's aims to foster community partnerships and support systems for people affected by hepatitis C. However, given both the divergence of the nature of these efforts from the original funding proposal and the not insignificant amount of effort required to maintain and develop the incubation relationship, we recommend that the HIPPO project director, advisory committee, and Health Canada come to a formal agreement regarding the nature of and resource commitment to these incubation activities, that the activities be formally incorporated into the evaluation framework, and that all activities related to support group incubation be documented.

6.7 Improve mechanisms for the project coordinator to report difficulties

While unforeseen difficulties are virtually certainty with community-based initiatives, the effective reporting and management of these challenges is critical to project success. We recommend a more effective information feed-back system be developed to permit the advisory committee and project director to be kept more closely apprised of existing or potential obstacles and delays to provide them with an opportunity for rapid assessment of problems and provision of clear direction to the project coordinator regarding appropriate actions to mitigate impacts, or to alter the work plan to recognize and accommodate an identified challenge. The coordinator should be given specific time lines for the completion of specific tasks, and delays should be reported and explained. By implementing a formal full-circle reporting system, all individuals involved with the project will have a clearer sense of the project's status, progress, successes and challenges.

6.8 Improved project documentation

Documentation of work undertaken as part of specific project activities is generally poor and inefficiently organized. While this is not an uncommon situation, particularly with community-based projects which are often run by individuals who are driven to serve the community and work with people instead of managing work flow, it does not make evaluation of these programs easy. Without routine, organized, and thorough documentation of work done in project activities, it can be very difficult to identify (and learn from) errors and successes. This is particularly true when primary data collection (such as the HIPPO physician and community-based organization surveys) is concerned. All information regarding sample frame selection, sampling, survey distribution and follow-up, and logging and coding of returning surveys must be carefully documented

and archived for future reference. All individuals involved with activities that produce a data stream for the project (for example, facilitators at hepatitis C information workshops) must comply with project protocols for measuring workshop outputs so that relevant information on the workshops can consistently added to the project documentation. We recommend that all staff participating in the chain of documentation of project activities be coached on the role of evaluation within the project, and the importance of their participation in supporting the data collection process.

6.9 Build capacity to improve data management

One shortcoming among staff at many community-based organizations is that many individuals with responsibilities for managing data have never received training in how to manage information effectively. The current evaluation framework includes many activities in which the effective management of project data can greatly simplify and speed the tasks facing the project coordinator. Unfortunately, our observations on site indicate that the present coordinator not only requires additional skills in effective data management, but is using software tools that are beyond his competency level and which he is using inappropriately—which will make analysis of the data entered in the software very difficult and will require costly investment of time to clean the data sufficiently to permit analysis. We recommend the coordinator receive basic training in record keeping for research projects, and that the project director consider obtaining a more appropriate software application for the data collection management and data entry. Further to this, we make two additional specific recommendations below.

6.9.1 Adoption of more appropriate database software for non-technical staff

Microsoft Access is currently used for all database applications on the HIPPO project. While Access does permit a novice user to set up a very basic functioning data base with relative ease, the interface is unnecessarily complex and it is difficult for a novice user to develop databases with such essential features as custom tab-order for rapid data entry, data validation rules and pop-up lists to control data entry, and an intuitive interface for both data entry and record selection. Adoption of more appropriate database software would permit robust, rapid, and effective database development by project staff, thereby increasing their productivity when managing projects requiring primary data collection, reducing error rates when performing data entry, improving the quality and useability of the data entered. It would also reduce the analysis costs as databases collecting clean data avoid significant costs incurred by staff or research consultants needing to clean data before using them.

We recommend that the project director and advisory committee examine alternatives to the Microsoft Access database program. In particular, we would like to suggest careful consideration of FileMaker, an intuitive and simple yet powerful program that contains all the functionality community-based research and evaluation initiatives are likely to need. The software can share data with Microsoft Office products including Excel. Trial versions of the software and further information can be found on the FileMaker web site at: http://www.filemaker.com/products/try_filemaker.html. Training courses in FileMaker are offered by Simply Computing in Kelowna, and Copley & Schneider would

be prepared to provide assistance and advice in the development of specific research and data management applications if local consultants were not available. In Appendix B we use a database created by Tobin Copley to illustrate how a relatively simple and easily created FileMaker database can be used to manage data collection and documentation of a mail-out survey very effectively.

6.9.2 Basic database staff training and on-going support as required

HIPPO project staff must gain a basic competence using and developing simple databases. We recommend paid time to attend courses or work with training books to improve these competency levels, and requirements of staff to meet expected competency levels in accordance with the project's investment in their training. Training in the use of Microsoft Access is widely available through courses, books, and on-line tutorials. Should FileMaker be adopted, training courses in FileMaker are offered locally, and books and on-line instructional resources are available for FileMaker as well. Regardless of what database software is selected for future use, resources should be set aside for on-going training for both existing and new staff. While the skills gained by staff will obviously be beneficial for the performance of the HIPPO project, investment in database skills training will help build database and evaluation research capacity generally.

6.10 Pursue additional funding opportunities

Investigation of additional funding to support Hepatitis programs in the Okanagan could help extend the scope of the HIPPO project and support future sustainability of its program elements. Opportunities for collaboration with other organizations sharing common objectives or servicing the same populations of interest may be also deserve consideration.

7 Concluding comments

The HIPPO project has benefited from starting with a set of clearly-articulated objectives and the early development of a companion evaluation framework that defined specific activities and the outputs, outcomes and indicators stemming from the activities. Substantial effort was invested in the development of the framework at the beginning of the project, and despite the challenges in implementation the project has encountered over the last two years, the framework remains useful and appropriate. Because progress toward the planned objectives has been slower than expected, a large amount of work remains to be done in the project's third and final year. Some reduction in planned activities—and program deliverables—will almost certainly be required in order to focus efforts on activities that can reasonably be completed in the time remaining.

In spite of the numerous internal and external challenges the HIPPO project has had to address, the project has already realized a number of significant successes, and remains well positioned to capitalize on its investment in planning and strong community connections. With respect to the challenges HIPPO has faced the project so far, it is in a good position since it has not met any fundamental obstacles to success: the difficulties that have been most responsible for its slower than anticipated progress can be traced to

issues in project management, focus, or implementation, all of which are tractable problems. By realigning project objectives to ensure all revised objectives can be achieved in the time remaining, making a concerted effort to address the project implementation challenges, and improving routine documentation of project process and outputs, the HIPPO project stands to be highly successful in 2002/2003.

APPENDIX A: HIPPO evaluation framework used for 2001/02 year

This Appendix contains the HIPPO's evaluation framework as of April 01, 2001. This version of the framework constituted the guiding document for the 2001/02 fiscal year. Short-, medium, and long-term outcomes are described where applicable and can be meaningfully articulated. We anticipate this framework will be revised for 2002/03.

Goal 1: Determine what services are available to HCV+ people in the North/Central and South Okanagan Region.
Objective: Using the principles of Community-based Research, establish an Advisory Committee and Compile data on Professional (physicians) and governmental (provincial, regional, local) for the delivery of Hepatitis C related prevention, care, treatment and support.

* Inputs – In all activities except those otherwise noted, the inputs are HIPPO resources-coordinator, office, supplies, meeting room, etc.

	ACTIVITY #1	**ACTIVITY #2**	**ACTIVITY #3**
ACTIVITIES	**Establish Advisory Committee for HIPPO**	**Survey of Physicians in the region (approximately 558 physicians identified in the ARC database)**	**Survey:** Community-based Social Service agencies in the region **Administration Officials of the Following Provincial Ministries:** Social Development & Economic Security Health Housing **Regional:** Local Health Units Regional Health Board Community Health Councils Aboriginal Groups
OUTPUT	Objectives for HIPPO set. Operations of HIPPO reviewed Management of issues as they arise	Questionnaires mailed Completed Questionnaires returned to HIPPO Analysis of Questionnaires	Agencies contacted by phone, fax or mail.
SHORT TERM OUTCOME	Collective knowledge and experience with respect to Hepatitis C is used to set goals and guide the HIPPO project.	Get a better idea of physicians' abilities to provide Hepatitis C services Build a database of physicians who: • have Hepatitis C patients (are aware they have Hepatitis C patients), • are taking on Hepatitis C patients (expressed a willingness to take on Hepatitis C patients)or, • have Hepatitis C expertise	Get a better idea of government abilities to provide Hepatitis C services Build a database of government agencies that are providing services or have developed policies for people living with Hepatitis C.
MEDIUM TERM OUTCOME			
LONG TERM OUTCOME			
INDICATORS	Goals specified Successes noted Problems identified Responses to problems, desired results and actual results	Responses in questionnaires returned	Responses to inquiries
DATA SOURCE	Meeting minutes	Returned Questionnaires	Returned questionnaires, structured notes from phone conversations
EVALUATION METHOD	Review of minutes	Analysis of questionnaires Development of physician database	Analysis of responses Development of a government services database

Goal 2: To develop and promote community based partnerships for the delivery of education and support to persons living with HCV
Objective: Develop a network of community based partners throughout the region for the delivery of education and support to persons living with HCV

	ACTIVITY #1
ACTIVITIES	**Interviews with representatives of Community Based Groups that indicated an interest in developing Hepatitis C capacity in Community Group Survey (see Goal 1, Objective 1)**
OUTPUT	Information collected from interviews Database of agencies and their Hepatitis C related activities
SHORT TERM OUTCOME	Start to develop a network or networks of agencies that provide Hepatitis C related services Develop a database of community agencies that provide Hepatitis C related services
MEDIUM TERM OUTCOME	Identify services that are not being provided, but are needed Develop strong networks of service providers
LONG TERM OUTCOME	Lays groundwork for development of needed services that can be delivered through existing or new community agencies (see Goal 6)
INDICATORS	Does agency have capacity to provide Hepatitis C information to clients? (at initial contact) Does agency have capacity to help completing Hepatitis C related disability claims (at initial contact) Contacts with HIPPO project Does agency have capacity to provide Hepatitis C information to clients? (at later contacts) Does agency have capacity to help completing Hepatitis C related disability claims (at later contacts)
DATA SOURCE	Database tracking community agencies, their Hepatitis C capacities and contacts with HIPPO
EVALUATION METHOD	Review of database

Goal 3: To promote sound information regarding Hepatitis C in order to minimize the discrimination and marginalization of persons infected with and affected by Hepatitis C. The target group for this is those living with Hepatitis C and those who are potentially at risk for contracting Hepatitis C (all those not infected).
Objective: Allow HCV to be better understood and appreciated on the part of the residents of the Okanagan Region, including dispelling any myths, misunderstandings and associated discrimination and marginalization of persons living with HCV.

	ACTIVITY #1
ACTIVITIES	**Generate and distribute information to the general public regarding prevention, care treatment and support for Hepatitis C.**
OUTPUT	• Promotional contacts through media. • Distribute appropriate press releases through Radio, TV and print. • Development, circulation, and rapid availability (internet?) of prepared Hepatitis C media packages fact sheets issue sheets human interest leads etc. (make coverage of Hepatitis C easy for them, path of least resistance, etc) • Development of relationship with media reporters, staff. • The distribution of Hepatitis C related materials at various venues
SHORT TERM OUTCOME	Increased awareness of Hepatitis C –how one can prevent becoming infected and the reality of living with the disease.
MEDIUM TERM OUTCOME	
LONG TERM OUTCOME	New infections averted Myths and Stigma of Hepatitis C reduced General public is better informed about Hepatitis C, how to prevent infection and care those infected need.
INDICATORS	Number of press releases put out Numbers of each type of information document distributed (process information)
DATA SOURCE	HIPPO Coordinator Process Information database
EVALUATION METHOD	Analysis of Coordinator's media file Analysis of Process Information database (distribution of materials, etc.) Track contacts with media (media contact database?) Possible Focus Group, involving representatives of the General Public

* This goal is similar to Goal #7, although the audience is more general.

Goal 4 : To empower people living with Hepatitis C to do self-advocacy and lobby for programs and services, guided by the principles of Population Health. To promote wellness and improvement in the quality of life of persons infected and affected by Hepatitis C
Objective: To establish community based programs and services for self-advocacy tailored to the needs of persons living with HCV and/or their caregivers.

	ACTIVITY #1	ACTIVITY #2
ACTIVITIES	**Needs assessment** **Consultation with individuals infected with Hepatitis C and/or their caregivers to determine skills and resources needed to support self-advocacy**	**Capacity building** **Work with community based programs so that they can provide tools necessary to help develop self-advocacy skills for those living with Hepatitis C and/or Hepatitis C caregivers.**
OUTPUT	Collect relevant information on services and support that is available and that which is needed.	Training and education of staff at community based agencies in identified content areas
SHORT TERM OUTCOME	Build a database that contains information on programs and services for which people living with Hepatitis C or their caregivers might engage in self-advocacy	Development among community based groups to train/educate individuals in identified self-advocacy areas.
MEDIUM TERM OUTCOME		
LONG TERM OUTCOME	"Empowerment" and effective voices lead to better opportunities for improved health outcomes for those infected with Hepatitis C and their caregivers.	"Empowerment" and effective voices lead to better opportunities for improved health outcomes for those infected with Hepatitis C and their caregivers.
INDICATORS	Development of database and any reports generated from this database (i.e.) summary stats showing frequency distribution of identified areas of knowledge/gaps among community groups)	Number of agencies in database and added over time Number of training sessions Number of staff trained
DATA SOURCE	Database listing self-advocacy skills that would be helpful to individuals living with Hepatitis C.	Database listing community based agencies and their capacity for developing self-advocacy skills
EVALUATION METHOD	Review of database (content analysis)	Review of database (summary statistics of activities of capacity building efforts)

Goal 5: To facilitate access to emotional, spiritual, social and practical support for person infected and affected by HEPATITIS C; respectful of their right to determine the direction of their lives.
Objective: Have in place a group of trained Peer Counselors to provide emotional, spiritual, social and practical supports for persons infected and affected by HEPATITIS C

	ACTIVITY #1	**ACTIVITY #2**	**ACTIVITY #3**
ACTIVITIES	**Peer Counseling Training (PCT) Program, based on the very successful program provided by the British Columbia Persons with AIDS Society**.	**Counseling sessions**	**Train the Trainer (TTT)- develop a TTT Program from the Peer Counselor Training Program**
OUTPUT	Development and implementation of PCT program for peer counselors	Clients receive counseling	Development of TTT Program
SHORT TERM OUTCOME	• Peer counselors trained. • Hepatitis C counselors have opportunity to help others living with Hepatitis C. • Development of a PCT programs for Hepatitis C • Development of program materials (make available to other organizations?)	Successful counseling results in better ability for those living with Hepatitis C to care for/support themselves	Ongoing support and opportunity to provide support for those living with Hepatitis C
MEDIUM TERM OUTCOME			
LONG TERM OUTCOME		Better health outcomes for those receiving and, potentially, giving counseling services	
INDICATORS	# Peer counselors trained	# Counseling sessions Total # persons receiving counseling	# TTT training sessions completed # Trainers trained
DATA SOURCE	Records on training sessions	Records on counseling sessions	Records on training sessions
EVALUATION METHOD	Review records Focus group of people who have participated in PCT program?	Review records Focus group of people who have participated in counseling sessions?	Review records Focus group of people who have participated in TTT program?

Goal 6 : To enable the provision of accessible services in a non-judgmental, safe, confidential environment
Objective: To help support Community based agencies throughout the Okanagan Region who are committed to provide accessible Hepatitis C services in a non-judgmental, safe confidential environment.

	ACTIVITY #1
ACTIVITIES	**Training of Community Based Agencies who have committed to provide the delivery of services and programs in each area (identified through Goal 1, Goal 2)**
OUTPUT	Training sessions for community agencies
SHORT TERM OUTCOME	• Agencies develop greater capacity to deliver Hepatitis C services in a non-judgmental, safe, confidential environment. • Increased sensitivity among community agencies to the needs and realities of those living with Hepatitis C+
MEDIUM TERM OUTCOME	Potential for CBO collaboration, undertaking partnerships in initiatives, and mutual support with lobbying, etc.
LONG TERM OUTCOME	
INDICATORS	# training sessions # agency staff trained feedback from agencies
DATA SOURCE	Training session records
EVALUATION METHOD	Review records Possible focus group involving community agencies that have been involved in training sessions

Goal 7: Determine what services are available to HCV+ people in the North/Central and South Okanagan Region.
Objective: Provide and develop new modes to deliver preventative education to the public and to specific target populations including Aboriginal peoples, youth, intravenous drug users and individuals involved in the sex trade.

	ACTIVITY #1
ACTIVITIES	**Using the current model of the ARC Speakers Bureau, train volunteers to deliver educational sessions to the identified community groups, social service agencies and governmental agencies.**
OUTPUT	Volunteer Training sessions held
SHORT TERM OUTCOME	Development of speakers who are well informed about Hepatitis C, who can go into communities and present information in a variety of forums.
MEDIUM TERM OUTCOME	Strengthened linkages to other organizations (especially those in which newly trained individuals work)
LONG TERM OUTCOME	
INDICATORS	Number of volunteer speakers trained
DATA SOURCE	Documentation of training sessions held and speakers trained
EVALUATION METHOD	Possible Focus Group with trained speakers to get input on strengths and weaknesses of training program and identification of potential areas for improvement

	ACTIVITY #2
ACTIVITIES	**Using volunteer educators trained in Activity #1 above, provide Hepatitis C prevention education sessions deliver educational sessions to identified community groups, social service agencies and governmental agencies.**
OUTPUT	Provision of Hepatitis C prevention education sessions Distribution of Hepatitis C Speaking Package(s)
SHORT TERM OUTCOME	Providing specific population groups of interest with relevant and understandable Hepatitis C prevention information
MEDIUM TERM OUTCOME	Change in knowledge or attitude regarding Hepatitis C Strengthened linkages to other organizations (in particular those organizations sponsoring educational sessions in which HIPPO volunteers make Hepatitis C prevention presentations)
LONG TERM OUTCOME	
INDICATORS	Number presentations made by speakers Number of participants attending sessions Favourable responses in workshop evaluation questions Favourable reviews from past participants in follow-up focus groups held with education session participants
DATA SOURCE	Database documenting presentations given Database containing responses from workshop evaluation forms Transcripts / notes from follow-up focus groups.
EVALUATION METHOD	Review / analysis of documentation and evaluation form databases Possible follow-up focus groups with past participants to learn what went well and what could have gone better.

APPENDIX B: Example of a simple coordinated data collection management tool

The collection of information to support program evaluation typically involves the structured management of several parallel demands on a coordinator's resources. A simple database application can be an indispensable tool permitting the coordinator to manage a data collection process, enter data quickly and accurately, provide simple descriptive statistics or output data files for later analysis, and produce template reports of program status nearly instantly. Some currently available consumer market database products are designed so that non-technical users can develop very effective databases of low to moderate complexity quickly. A one to five day investment made developing an integrated set of databases to manage a project's data collection, data entry, and to assist with project status reporting should be justifiable for many projects when the downstream time savings and increased effectiveness are considered.

In this Appendix, we provide a very quick look at a simple database by created Tobin Copley to manage data collection for a mail-out survey. The database shown here was designed to help Tobin maximize the survey response rate by ensuring that the status of each mailed questionnaire was always tracked and documented, that the project status could be summarized instantly for review, and that action could be structured and prioritised to maximize the efficiency of effort expended. All mailing labels for new or replacement questionnaires were generated from the database; any address corrections made in the database would carry forward automatically to mailing labels. The actual survey project on which this example is based took five weeks to complete, and the client was given weekly status reports. The generation of the documentary portion of the status reports took less than five minutes per week because they were generated through custom-designed standard reports. The database shown here did not include a module for the entry of information from completed questionnaires, but it would not have been an onerous task to have done so. The basic framework for this database, including porting all the contact information for the sampled organizations into it, was completed in well under a day. A series of incremental refinements was made over the course of the project as specific needs required, but less than two days work was required to produce a tool that was essential for the proper management of the process.

Figure 1 below shows a sample layout that provides a overview of the status of one of the 230 records in the database. The upper half of the screen shows contact information for the case, their current status, and a review of what information they have been sent when. This is the main screen used when calling individuals back as we worked to get them to complete and return the questionnaires. The lower half of the screen contains a history of every contact made in connection with the questionnaire for the case. The button in the upper right selects those cases which are ranked highest priority and which fall into a time window in which call-back action is appropriate (e.g., more than a week since a follow-up letter was sent).

Figure 1: Database layout showing the current status of a fictitious sampled individual

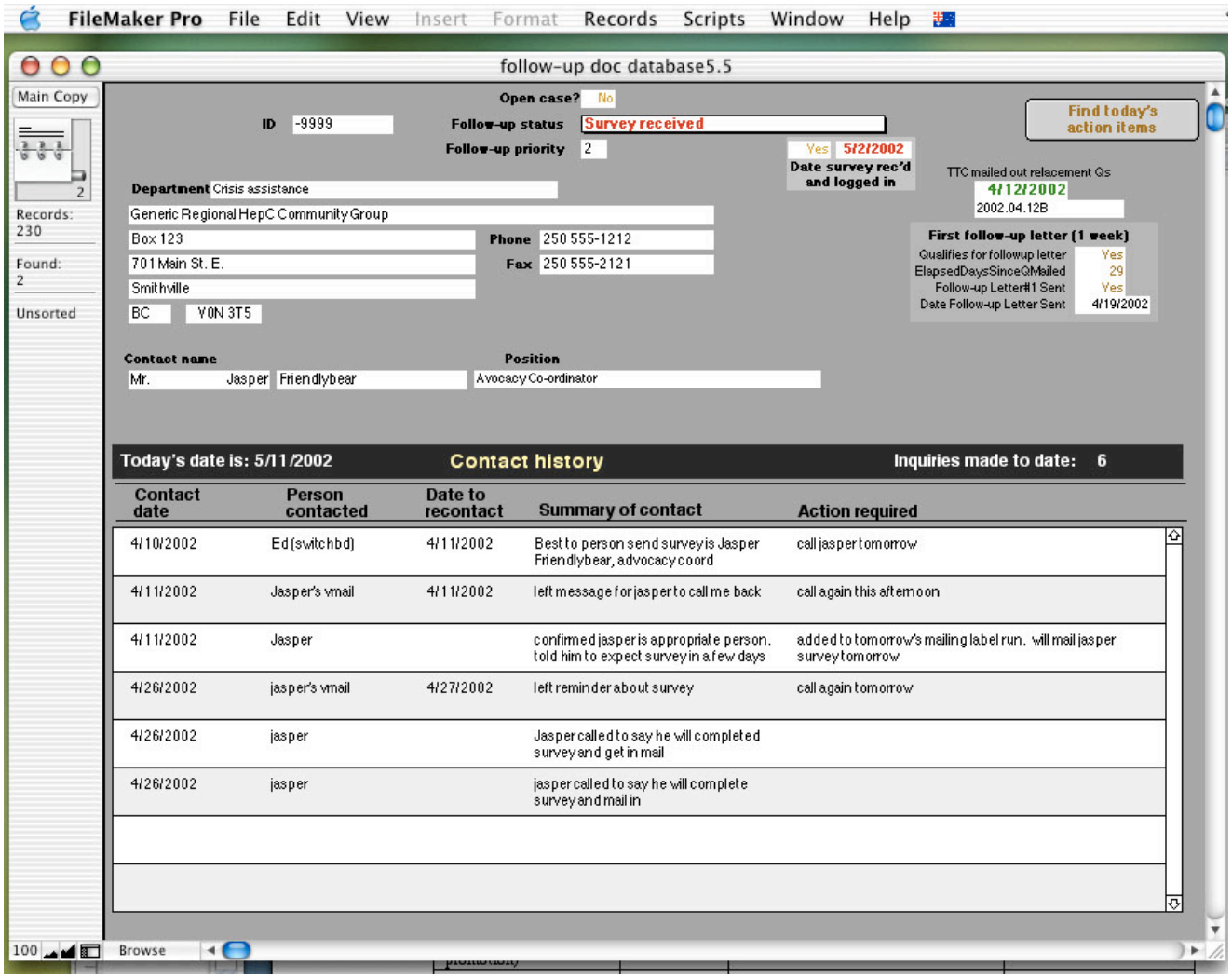

Figure 2 shows another view of the same data set, this time providing a summary overview of the current status for every case in the database. This view provides excellent documentation of the state of the project, with every case classified within a logical organizational scheme. From this chart, users can select cases meeting specific criteria (such as cases in which individuals have been identified but from whom we have not yet received a completed survey), and sort them by priority and/or the date they were sent the survey. A number of other layouts developed in the database have not been included as part of this Appendix.

Figure 2: Database layout showing status overview for all cases in the database