

Exploring a Virtual Centre for Community-Based Research

By Terry Trussler and Rick Marchand

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Study Advisory Group: Barry Adam, Dan Allman, Yves Jalbert, Lynne Leonard, Darien Taylor, Martin Dockrell (UK), Heather Worth (NZ)

Technical Advisors: Scott Carley, Beth Hawkes, Jason Holmes

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Introduction

This report examines the feasibility of developing and maintaining a web site devoted to HIV/AIDS community-based research (CBR) in Canada.

Creating supportive structures to develop community-based research has been an ongoing discussion for many years prior to and since consultations leading to the current Canadian Strategy on HIV/AIDS. The idea of a *virtual centre* to coordinate these efforts has been referenced many times in the intervening years. To move the agenda forward, The Community-Based Research Centre (CBRC) proposed a feasibility study to explore the virtual centre concept. The CBRC is itself a Vancouver-based non-profit agency mandated to support the knowledge development work of other community organizations.

We explored the feasibility of a *virtual centre* for CBR from five perspectives:

- the qualities of CBR currently in practice in community HIV/AIDS groups
- what community personnel desire from CBR and its development
- how web technology could facilitate capacity building for CBR
- what users would want from a CBR site
- what kind of approach and extent of investment would make a web site effective for community research capacity building.

Many reasons have been put forward for developing a web site dedicated to CBR.

Participants in community HIV/AIDS research have been seeking an effective means to:

- enhance the development of strategic local knowledge about HIV
- support evidence-based community planning and programming
- coordinate community-based research resources
- encourage networking among researchers and communities
- facilitate mentorship among new and experienced community researchers
- encourage communities to understand and use research
- build the capacities of communities to undertake CBR
- support the ethical review of community research
- provide a medium for dissemination of community research

In the long run, participants have argued that the supported expansion and development of CBR would:

- assist communities in addressing local prevention, support and care issues
- enable communities to better address health care systems about local HIV vulnerabilities

Our research, *likely the first empirical study of CBR in Canada's community HIV/AIDS infrastructure*, has shown that the basics are in place for a web-based capacity building program. Most community HIV/AIDS groups currently have computers and access to the internet. Computer accessibility is steadily improving. Community personnel have expressed a great desire for skill building and networking opportunities. Many with experience in community-based research want to contribute to the development of the site while expanding their own capabilities.

Although we have found that the internet has its limitations, the *virtual centre* concept has many advantages and offers a realistic and cost effective strategy to enhance system-wide capacities for HIV community-based research. The desired effect of this kind of investment is to reduce HIV/AIDS costs over all by building community capacities for more effective control over local HIV/AIDS vulnerabilities.

No site currently exists for HIV community-based research. A variety of sites offer useful information on social research but none exists that is dedicated to the knowledge development efforts of communities. Certainly, no web site exists with a mandate to encourage excellence among community participants in HIV research. Indeed the potential for a productive engagement in developing community research capacities via the web extends well outside of Canada to the rest of the world.

We consulted with researchers, community personnel, web developers, and experienced academics with adult learning and web education experience, inside and outside of Canada to build a model of the kind of site that would best suit capacity building community-based research on HIV/AIDS. What follows is the complete report of what we did and what we found.

Methodology

In undertaking this study we adopted a mixed method approach. We had specific information needs concerning the design of the site but also about potential audiences and community-based research as currently practised.

We had five leading questions.

1. What is community-based research like right now?
2. How can CBR be supported for further capacity development?
3. How would a web site help?
4. What would an appropriate site be like?
5. How would we go about building it?

We made use of several strategies to obtain data.

- Survey
- Interviews
- Case stories
- Workshop-consultations
- Pilot site development

Survey

We conducted a survey of volunteer and staff personnel working in community based HIV/AIDS organizations. We theorized this would be one of several potential audiences for the site but a prime one and one that might come to depend on the site for research assistance.

We created a questionnaire to probe their use of information for planning and decisions, current experience with research activities, use of computers in community HIV/AIDS work and features of a useful community research site. We trial tested the questionnaire locally and piloted a revised version at a national workshop.

Our goal was to obtain a regionally diverse sample of 100 respondents from across Canada. To solicit participants, we made strategic use of a series of regional research capacity building workshops held across Canada while our study was already under way. Survey participants responded by fax and email. We received 103 completed surveys from a diverse range of personnel located in communities across Canada in most provinces and territories except Nunavut and Prince Edward Island.

Interviews

We sought key informants from three Points of view.

- Potential User-Contributors
- Web experienced community personnel
- Experienced web developers

We used both telephone and email to conduct interviews. Telephone interviews were transcribed. We were interested in different kinds of questions from each of these groups.

Potential User Contributors

This group of experienced community based researchers might well be expected to use the site in their work but also to participate in its development. We wanted to determine their level of interest in a CBR focused site, what they would find useful and what they might wish to contribute.

Web-experienced community personnel

We examined existing web sites of community based HIV/AIDS organizations across Canada. From that list we determined that four were current and active with large amounts of searchable detail.

- AIDS Committee of Toronto
- British Columbia Persons with AIDS Society
- Canadian HIV/AIDS Legal Network
- Community AIDS Treatment Exchange

We spoke with both administrators and web service personnel to get their impressions about the operation of active web sites, the organizational burden they experienced and their suggestions for the future CBR site.

Experienced web designers

We sought out professionals who we thought of as potential consultants or developers of a site for community-based research. In approaching the field in this way we learned to discern those who had more or less affinity with the project. We selected the most likely for in-depth interviews. From this group, we wanted to know how web technology could be used to build community research capacities in the best possible ways.

Case studies

Several projects on community-based research happened to converge with the web feasibility study. We had established a case story reporting system for CBR experiences in two previous projects. We obtained a diverse sample of both international and national experiences. This data helped to shape a sense of the status of CBR as it is currently practiced and therefore how a web site might address capacity development from where people are now. In establishing this baseline we thought it might also be possible to discern change once a site had been launched and active for a period of time.

Workshop-consultations

Recent consultative workshop experiences on community-based research also provided useful insights into web-based capacity building: a Satellite Symposium held in conjunction with the 4th AIDS Impact Conference in Ottawa, July 1999 and a Satellite Workshop held in conjunction with the 2nd Canadian Skills Building Conference in November 1999. The AIDS Impact Satellite not only provided international perspectives on CBR but also produced a consensus statement on the conduct of CBR. We also obtained useful data on current practices, needs and issues from the 2nd Canadian Skill Building Symposium.

The most important meeting of the feasibility study itself was held in Vancouver in March 2000. We invited an advisory panel that included two academic researchers conducting community research, three researchers based in community organizations,

and two community-based researchers from outside of Canada. We also invited three web development advisors. Two policy advisors from Health Canada were also in attendance.

At this meeting two experienced developers from the Educational Technology Department of the University of British Columbia presented an orienting framework for what the web might do for the conditions we were facing. We presented data from the survey and interviews. The committee responded with intense discussions of various issues that needed to be considered in building the site. We documented the meeting on audio tape. We took notes and selective quotes from those tapes to provide direction for the development of this report and the pilot site.

Pilot site development

Certainly one of the more important sources of information for this study came from direct engagement in developing a pilot demonstration site. We undertook continuing education opportunities on web development offered at local colleges and universities. We identified potential technical assistants and interviewed them. We underwent a complete planning work-up for the site that included its first content items and array of site functions. We also wrote and distributed a request for proposals (RFP) for the pilot site's development. Finally we selected what we felt to be the most suitable proposal and established the team to build and publish the site.

We have included examples of strategic documents used in building the pilot site in the recommendations section of this report.

Community research as is

We uncovered some important details about the extent and qualities of community based research as practiced within Canada's community HIV/AIDS organizations in the course of this study. The data we gathered from surveys, case stories, interviews and workshop-consultations paints a picture of community research that previously has never been available.

More than 80% of our survey respondents reported some form of research or evaluation activities in their community organizations in the last year. This was a surprising finding considering previously held images of CBOs as either resistant, under-skilled or too busy to engage in research.

We have interpreted research to include any engagement in systematic data gathering and analysis to produce evidence for decisions. While more rigid constructs of research exist that would demand more, such as a promising contribution to new knowledge, we believe the simple engagement in inquiry by itself is somewhat of a revolution in the practices of community HIV/AIDS organizations.

We found many reasons why this interest is growing, most of them practical. Our survey showed that 60-65% of respondents felt impeded in their work by a lack of local analysis of HIV vulnerabilities or documentation of HIV risks. *Their predominant interest in research revolves around community program development and evaluation.* Community organizations want to know how best to serve in local conditions. They also want to know if what they are doing is working.

When asked to list their top research priorities, 70% of our survey respondents indicated "program effectiveness". The next two most popular responses were "local patterns of risk" at 55% and "local vulnerabilities" at 45%.

Review of case stories and transcripts of workshop-consultations indicate a range of potential topics for CBR. While there is certainly interest in community-based prevention research, there is also an impressive demand for more knowledge about community-based support, treatment and care. Community HIV/AIDS organizations are delving into such issues as undocumented side effects of HIV medications, workplace issues for long term survivors, complementary treatments and the hidden economy of community involvement in care, to name only a few.

The top 3 sources of information for planning indicated by our survey respondents were 65% "research findings," 63% "published literature" and 62% "evaluation", respectively. When we asked how they usually get information about local conditions 69% of our survey respondents indicated "informal discussions" but 65% reported using "interviews" and "focus groups".

We have not pursued any analysis of the methodological rigour of those studies. Nevertheless, our data show that community HIV/AIDS organizations are earnestly engaging in research activities to produce evidence upon which they may make responsible decisions. The goals of such purposive research are quite often different from the goals of science. While scientific and community interests sometimes converge,

community organizations are more likely searching for insight concerning their impact and effectiveness. Their interests are not about producing broadly applicable principles of scientific knowledge but about doing the right thing, the right way for the least cost.

Even more to the point, whatever is being experienced now with research activities in community organizations is still in development. *If this inherent interest is to be cultivated and encouraged, policy, funding and capacity building efforts need to be developed to meet community agencies where they are with a good understanding of their practical needs.* This, we believe, is a fundamental principle that would be taken up in the design of a web site to support community-based research.

Key Points

- More than 80% of survey respondents were involved in research last year
- Predominant interest is in program effectiveness
- Inherent interests in research best cultivated through practical approaches

Community research as wanted

Our inquiries into the feasibility of the web site uncovered strategic details about what community personnel desire from community-based research and its further development. We felt it would be important to know what community personnel are thinking about the future of their research in order to be able to anticipate their natural desires in the development of the web site.

We asked survey respondents what kinds of research they thought would help their work. About 65% of them rated “local surveys”, “program evaluation” and “in-depth interviews” as priorities. About 60% rated “focus groups” as a priority, followed by “literature analysis” at 46%. This and other indicators revealed relatively similar interests in both quantitative and qualitative methods. Interest in “program evaluation” reinforces a widely expressed need to know more about “program effectiveness.”

We also asked respondents to assess what skills they felt they needed to upgrade in order to pursue community-based research more effectively. About 65% indicated “research software” and “qualitative methods” as priorities, 61% “quantitative methods” and “evaluation”. By contrast, only about 48% indicated needing to upgrade their “literature review” skills.

While we generally found the personnel we dealt with throughout the study to be enthusiastic about developments in community-based research, those sentiments were certainly not universal. At the 2nd National Skills Building Symposium in Winnipeg participants expressed doubts about the direction Health Canada’s policies were taking community-based research. They expressed concerns that community organizations were now being expected to conduct formal research, potentially at the expense of their programs.

At the same time, they also recognized that governments are now expecting community groups to provide evidence for both program needs and effectiveness. In this way, they can see that research skills may benefit program development and planning activities. So they conclude that there should be better coordination and integration of funding to *combine programming with community-based research*. They strongly expressed the view that the current format for funding CBR under the auspices of the National Health Research and Development Program (NHRDP) recognizes only formal research activities, accessible only to the most advanced community organizations and also with some form of professional, or highly skilled support.

The research that community organizations want to do is best expressed in the topics they are trying to grapple with in the day to day life of communities and their organizations. We asked participants in a workshop-consultation to develop a list of priority topics for community-based research. Their list provides an interesting snapshot of what the future of community-based research might look like if community organizations are successful in launching their CBR projects.

CBR topics

Care & Treatment

- Ongoing quality of life change: periodic assessment as conditions change
- What do PHA's need when health has improved?
- Legal, discrimination problems
- Employment issues for PHA's
- Staying at work – work related treatment issues
- Mental health issues related to HIV
- Post-approval drug surveillance
- Side effects of current therapies
- Street drugs and complementary therapies
- Interaction between prescription/nonprescription drugs

Preventing Transmission

- Attitudes: risk behaviour, homophobia, decision making, sexual choices
- Social conditions and patterns that create risk
- HIV prevention for women
- Group vulnerabilities

Policy & Program

- Changed demographics (same resources: new populations) how to manage
- How to distribute resources fairly to include all infected/affected groups
- About partnership and collaboration in HIV/AIDS work

Marginalized Populations

- How to provide services to marginalized: rural, IDU, children
- Risk factors of marginalized communities
- How to change service relevancy for marginalized

When we asked our survey respondents whether they would be interested in a web site devoted to developing community-based HIV research, 60% indicated they were “interested” and “could use the resource”, and 40% said they were “very interested” and “would like to contribute resources”. We felt this was a very promising indication about future participation in developing community-based research and a theme for the development of the web site.

We also asked survey respondents what features they would most like to see developed on a web site for community-based research. Over 70% indicated “archived reports” as a priority. More than 60% indicated “research tools” and “skill building as priorities”. By contrast only 25% felt a “discussion forum” was a priority.

We found the interest in “archived studies” resonated throughout the study especially in interviews with key informants and the most experienced community-based researchers. It is clear from all the evidence we gathered that *community personnel want to learn from each other's work* and they see that a web site location would be a good service to help them in that effort.

When we asked our survey respondents about barriers they saw in using a web site to their research work we got an interesting take on the demands of community life and the place of research within them. Over 63% saw time as their greatest barrier. By contrast, only 18% saw funding as a barrier.

Key Points:

- Major interests in research: program effectiveness, surveys, in-depth interviews
- Concern about formal research agenda interfering with programs
- Desire to integrate research with programming
- Communities' research agenda driven by practical needs
- Demonstrable interest in web based research skill building
- Time seen as a greater barrier than funding
- Community personnel want to learn from each other's research

Role of the web

We wanted to know how a web site would be used in capacity building for community-based research. To develop this appreciation, we consulted a variety of resources:

- Experts in web-based applications for education
- Web experienced community HIV/AIDS personnel
- Online web design resources
- Web development textbooks

Virtually everyone we consulted thought of our web site's concept – building community capacity for research – to be an excellent idea, rich in development potential on a global scale, and essentially “*what the web was actually created for.*”

We found there was strong *compatibility between what experts said the web does best and best practice in community capacity building.* Building community capacities, as any developer knows, involves more than technical capabilities alone. Fundamentally, capacity building is about community building.

Community personnel themselves have already recognized their need to connect or to “network” with others for mutual support, mentoring and consultation -- *building their research capacities by involvement in a community of community researchers.* What the web seems to do best is to link people of like interests to enable such community building.

In this sense, the web is one tool amongst many, albeit a powerful one, that people may use to help organize and develop both their capacities and communities. People need face to face connection above all to participate in community but the web is a powerful, new tool in helping people find and maintain such connections. Certainly one segment of the world wide web is devoted to building “on-line communities.” One site “egroups.com” offers itself as a free service to help groups from anywhere establish on-line communities.

Community Building Strengths of the Web

- Linking people and ideas
- Facilitating and recording interaction
- Coordinating people, plans and actions
- Publishing and distributing information
- Responding to developments quickly

We also found that the web is being used in various ways that do not always meet with these ideals. Because the web is such a new and novel medium, experimentation is to be expected. We felt that it was important to try to match our intention to engage in research capacity building with what role the web could best play.

We believe that capacity building is another term for learning, sometimes involving individual learning and sometimes whole communities. As we discovered, web experts are very interested in the way people learn when using the web, because it is vital to doing successful business on the web.

Learning on the web

- Intentional learning
- Associative learning
- Collaborative learning
- Learn to

Intentional learning has been studied for more than thirty years in adult education research. Simply put, intentional learning is *about people learning on their own without a curriculum to satisfy their needs and curiosities, at their own pace*. In this sense the web is a vast library that facilitates such learning at any time and any place for anyone with access to a computer.

Associative learning refers to the incidental learning that people undergo as they pursue their intentions but find more than they were looking for because *they see new relationships between things*. Expertly designed web sites are being created to facilitate associative learning because developers recognize that this quality keeps people interested and more likely to return to the site.

Collaborative learning is about *people learning from each other*. Studies have shown that students learn more from each other than their teachers. Expert instructors try to facilitate this collaboration. Web developers have recognized the importance of this phenomenon in designing distance learning courses for the web. But the web can do more for distance learning than offering a prescribed course. The people taking it can use web technologies to communicate with each other and create a community of interest.

This where a similarity between collaborative learning and community-based research begins to take shape. Research, after all, is a form of learning, albeit formal, systematized and focused on the unknown. We discovered that CBR is known as “collaborative research” in Australia. Actually, it is intense collaboration within communities that distinguishes community-based research from other forms of scientific inquiry. The web makes it possible because of its communicative strengths.

Learn-to is about purposive learning. The web offers capabilities to arrange “learn-to” opportunities to anyone anywhere. In fact one commercial venture is known as learn2.com. University and college courses offered to students anywhere in the world are other examples. We found from our inquiries that while learn-to is possible it is not always the best way to encourage learning on the web. Because the web is so powerful in facilitating other forms of learning, web developers tend to prefer designing sites that work with the way people use the internet to satisfy their free ranging curiosity and work interests.

Key points

- Web best facilitates intentional, associative, collaborative learning
- Building capacity is about building community
- Web site will be useful in network building and partnering for CBR

Site design wants

We interviewed web-experienced community personnel and academics involved in CBR about the features they would like to see on the web site. We developed an impressive list of features that might serve as a blue print for the future of the site. The list is more than can be managed in the beginning stages. Still, the input of our key informants, about the way in which such a site could be useful to them and about how they could see using it in their work, was important information indicating the kind of site we would need to build in order to meet users on their terms.

We learned from expert developers that good site designs are user-centred, or constructed and written to appeal to the user rather than the organization that publishes it. This is where, we learned, that many web sites go wrong in development. Without keen focus, sites can end up being developed for the tastes of an organization's executives rather than the mind-frames of the users. For *the CBR site to be useful, usable and user-centred we would need to carefully consider what our key informants told us* about the design of their ideal site.

User-mentioned site design considerations

- Interactive (*most mentioned want*)
- Simplicity, easy to use, navigate, download, post & contact
- Accessible language and literacy levels
- Manageable information on each page
- Current, up-to-date, "returnable"
- English and French mirrored, but not necessarily completely
- Confidentiality protected and limits clarified
- Indexing and search functions available
- Cross cultural sensitivity for global users

Our key informants and potential site users gave us a range of ideas that would help them with their work and the general development of CBR as a practice. We found that their *interests were very practical and largely governed by the amount of time they have for the internet while at work*. As such, there was less interest in theoretical issues such as CBR's fit within social science than in useful features like tips and tools that would help them get on with their research.

Main user-mentioned functions for a CBR site

- Information about CBR
- Connection with other CBR personnel
- Partnership opportunities between academic and community researchers

Our key informants had strong ideas about what kind of site was best suited to their work environments. One of the predominant themes we heard was to *make the site a place where we learn from each other*, echoing the collaborative learning aesthetics of expert designers. In this way our key-informant/potential-users indicated that the web site should allow them to share their experiences with other community researchers, locate each other while studies are in progress, and to learn from each others' reports.

User wants from a CBR site

- Repository of research reports (*most mentioned want*)
- Research tools and templates
- Case stories of CBR
- CBR events and deadlines
- Funding source guide
- Ethical Review: about, guidance, access
- Annotated links to related web sites
- About CBR: concepts, theories, principles, references

We found that comparing this list with currently publishable resources was a sobering exercise. We would not be able to start a repository, for example, without a detailed work-up of a plan to solicit and review reports for publication. We could gather a good impression of the kind of site that would suit the CBR audience but we would need to consider how to build toward it over a period of time. Further, to meet current needs, demands and issues in the field, we realized that we would need to be able to operate the site as we build it.

The main clue to how a site might develop with its users came from the potential users themselves and their need for interactivity. This suggested to us that we would need to create a framework for a site that would anticipate the contributions of the users. At the same time the first appearance of the site would need to be interesting enough that users would not leave disappointed.

We also recognized that there would be time and work involved in creating units of learning to answer the needs of community personnel for learning about specific CBR issues.

User specified learn to's

- Writing research objective and proposals
- Active listening
- Taking field notes
- Focus testing
- Developing message campaigns
- Outcome evaluation
- Organizing research projects and teams
- Research on the internet
- Using research software
- Ethical review procedures
- Submitting for ethical review

Overall we found the features and functions desired by our key informants in step with leading ideas about the use of the web for both commercial and community purposes.

Key Points

- Site usability is a function of user-centred design
- High demand for interactivity
- Repository of completed reports most wanted feature
- Learning from each other most mentioned theme

Organizing behind the site

As we spoke with web developers and web-experienced community HIV/AIDS personnel we began to recognize that there were critical organizational issues to consider in developing a suitable site for our intentions and user considerations. *The need for interactivity, collaboration, publication and regular updating would all demand the presence of personnel behind the scenes.* The roles would vary between technical, content and organizational focuses but nevertheless they would be crucial to site operations.

Typical roles

- **Technical Administrator**
 - Manages software, host relations, site maintenance, updating
- **Content Manager(s)**
 - Arranges topical contributions, editing, editorial style, uploading files
- **Online Community Organizer**
 - Moderates forums, answers queries, member info, event coordination

We also began to recognize that the close connection between web-sites and any other form of publishing would mean there would be *a need for editorial functions with a certain amount of expertise in subjects under review.* When we compared the list of subjects that CBR personnel indicated were ongoing or intended, we began to see that there could be a need for several editorial advisors or contributing editors.

Content Editorial Roles

- Prevention Research
 - MSM, gay men
 - women
 - IDU
 - Aboriginal
 - Ethnocultural
- Treatment Research
 - Post approval surveillance, side effects
 - Rehab, adaptation, back to work
 - Care burden, costs, outreach
- Evaluation Research
 - Program evaluation
 - Outcome evaluation
- Community-based Methodological Research
 - Qualitative, ethnographic, interpretive approaches
 - Quantitative, survey, data ase, random control trial
 - Critical theory, post-modern, cultural studies

While this list appeared daunting from a project start-up point of view, we also began to recognize that there would need to be a *phased-in approach* to these developments. A combination of voluntary, part-time and full time personnel could be assembled to monitor developments in these subject areas, solicit material from community researchers and usher reports through pre-publication editorial processes. Nevertheless, overall

coordination and management of the program would require supervisory personnel such as a “content manager” as suggested above.

Online Community Organizing

Once we recognized that the web site would be a tool for community capacity building *we also had to consider the real rather than virtual aspects of the community we were building*. At international and national meetings, prior to the feasibility study, our potential users were already recognizing the value there would be in formalizing networks of community researchers for mutual support, collaboration and skill development. Our web development advisors contributed an important idea in this vein: *the site should encourage deep involvement in non web-based communities*. The web site, in other words, would function as a virtual meeting space in which to organize face to face collaboration and events among community researchers.

Network Management

- Hosting and moderating discussion groups, on-line conferences
- Posting news items and event notices
- Publishing an on-line newsletter
- Coordinating an expert panel for answers to information queries
- Managing membership applications, data bases
- Updating member to member contact information
- Arranging and coordinating real-time events such as workshops and conferences

Organizational Development

As we began to consider all of the above, we realized that the virtual centre for community research, which had been under discussion for several years, would be a much more complex undertaking than originally foreseen. The virtual centre would require a real organization behind it and with that all of the administrative and development issues of any organization. Because of the personnel involved, such would be the case whether the site was housed in an existing or dedicated organization.

This then led us to conclude that the major aspects of investment in the site were not in the site itself but in the people and organization behind it. Consideration would need to be given to recruiting personnel. Would the roles be filled by contract personnel, or full-time employees, or combinations of both? Would we eventually need to consider housing the organization at one location, or could personnel contribute to the site from remote locations in regional centers or their own offices? We would also need to consider all of the administrative, financial management and fund development aspects of any functioning community HIV/AIDS organization.

Key Points

- Interactivity demands behind the scenes personnel for site operations
- Phased in approach required to meet overall goals
- Technical, content and community organizing roles
- Editorial roles for subject fields
- Major investment not the site itself but the people running it

Recommendations

In considering all of the foregoing we developed an inventory of site functions to guide the development of a pilot site. Our site developers strongly advised planning extensively for as much future expansion as could be anticipated at a permanent site. When we took this approach we could see much more clearly how the organization behind a permanent site might grow as new functions were added and user traffic developed.

Our site developers needed direction from us to develop the site's architecture. We developed a site function-organization plan (*see chart A.*) to assess the amount of work involved in sustaining its activities. From this we identified several part-time roles or activity fields that would be needed for future development.

The pilot site design (*see chart B*) incorporates all that we learned from the feasibility study and thus stands on its own as a demonstration. The full development of a virtual centre, however, would be mounted in phases at a permanent site. (*see chart C*)

Recommendations

1. A web site should be developed and supported to assist capacity building for community-based research on HIV/AIDS.
2. The web site's prime purpose should be to strengthen the development of local HIV/AIDS knowledge capacities and resources.
3. The web site's design should be "user centred" to facilitate collaboration, network building, peer discussion, mentorship and partnering.
4. The web site should feature the exchange of experiences and findings from community-based studies to facilitate collaborative learning and peer review.
5. The web site should be supported with adequate resources to maintain a suitable staff dedicated to the development of both its content and its user communities.
6. Construction of the web site should be phased-in to allow time for the development of practices, policies and procedures.
7. The web site should be organized for research on community-based research in order to facilitate future evaluations of its impact and outcomes.

Once a permanent site is launched, we anticipate there will be extensive work in making its existence known. Some of that work would involve using email lists to announce and guide CBR networks to the site. Site developers have also suggested a separate strategy to use internet services such as search engines and link exchanges with existing HIV/AIDS related sites for promotion.

Undoubtedly these efforts will bring increased attention and activity to the site. We would expect that these activities will generate inquiries and offers to contribute case stories, reports and tools. *The phased-in approach we are recommending anticipates increasing user traffic and therefore more demand on the organization over time.*

We also anticipate more extensive activities developing around content communities associated with the site such as youth or aboriginal prevention, adaptation to treatment and so on. This will in turn create demands for review procedures and editorial services. In addition, *we recommend adding advisory panels and developing internal policies as functions and services are added to the site.* Future additions such as tutorials will require separate design and development cycles before they would be made available on the site.

Summary of Key Points

Current Research

- More than 80% of survey respondents were involved in research last year
- Predominant interest is in program effectiveness
- Inherent interests in research best cultivated through practical approaches

Future Research

- Future interests in research: program effectiveness, surveys, in-depth interviews
- Concern about formal research agenda interfering with programs
- Desire to integrate research with programming
- Communities' research agenda driven by practical needs
- Demonstrable interest in web-based research skill building
- Time seen as a greater barrier than funding
- Community personnel want to learn from each other's research

Role of the web

- Web best facilitates intentional, associative, collaborative learning
- Building capacity is about building community
- Web site will be useful in networking and partnering for CBR

Desired Features

- Site usability is a function of user-centred design
- High demand for interactivity
- Repository of completed reports most wanted feature
- Learning from each other most mentioned theme

Site Organization

- Interactivity demands behind the scenes personnel for site operations
- Phased in approach required to meet overall goals
- Technical, content and community organizing roles
- Editorial roles for subject fields
- Major investment not the site itself but the people running it

Chart A

Function-organization plan

Function	Capacity Goal	Technology	Organization	User advantage
Network	Develop community researcher network, list ongoing projects	Data base, member only access	Community-network development, data base and maintenance PTE	Access to ongoing studies, employment opportunities, peer support, mentorship
Forum	Online peer discussion & support. Special topics. Online conferencing	Conference software support	Moderate & edit contributions Editorial policy Special events co-ord PTE	Peer to peer queries and collaboration
News	Routine update on CBR studies and issues, policy advisory, funding sources	Searchable back issues	News column writing compilation and editing PTE	In touch with trends, problems and issues Informal publishing of CBR experience
Case Stories	Collection & analysis of cbr experiences	Case story template and submission form	Soliciting, editing compiling and periodic analysis PTE	Simple and direct interactivity, learning. Access to case examples
Reports	Repository of completed studies for user reference and critique	Transferable file formats. Storage issues Search functions	Solicit and coordinate review procedures Editorial policy & oversight committee 2-3 PTE's	Access to informal publishing and electronic distribution
Tools	Assist data collection and analysis of cbr in local contexts	Downloadable templates, software	Solicit and create tools for specific CBR applications PTE	Contribute tools Access to tools
Experts	Online queries on CBR issues, ethics & methods	Form submission Email return Searchable record of expert advice	Expert answer panel Coordination and maintenance of panel activities PTE	Specific advice and searchable long term query documentation
Tutorials	Online support for specific research topics & methods	Stepwise presentation Storage and retrieval	Tutorial development Solicitation of topics Coordination of contributors PTE	Basic training tool for typical CBR skills & methods
Search	Search site for user centred interests	Search tools	Indexing of site content, ongoing additions PTE	Access to site content by keyword index

*PTE = part-time employment

Chart B

Site architecture

Mission	Site content	Navigation
cbr.org	<ul style="list-style-type: none"> ▪ Describe site operations: <i>plans</i> ▪ Who runs it. ▪ Network description: <i>Join-up</i> ▪ <i>Contacts</i>: email ▪ User <i>survey</i> 	<p>English /Français</p> <p>Orientation Who's who Join Contact</p>
cbr policy	<ul style="list-style-type: none"> ▪ Policy initiatives ▪ Advisories: funding, ethical issues ▪ News column ▪ Searchable back issues 	<p>News Views Events</p>
cbr capacity	<ul style="list-style-type: none"> ▪ <i>Models</i>, guiding principles, <i>ethics</i>, case stories ▪ Forum – <i>moderated topics</i> ▪ <i>Ask Us</i> query – searchable ▪ <i>Tutorials</i>: learn-to ▪ Links, annotated gateway ▪ Publication order form 	<p>Methods Tools Forum Ask Us Links Publications</p>
cbr studies	<ul style="list-style-type: none"> ▪ <i>Tools</i>: templates, software ▪ Community Studies: <i>Prevention, Treatment, Care, Methodology</i> ▪ Studies of CBR: <i>Cases</i>, analysis ▪ Submissions: abstracts, papers, ethical review ▪ Search 	<p>Studies Submissions Search</p>

Chart C

Phases of development

NETWORK BUILDING

Network	Build membership, categories and database, develop mentorship program
News	Establish news column and reporting procedures
Tools	Solicit tools and templates for editorial consideration
Skills	Solicit "ask the researcher" expert query volunteers, FAQ data base
Reporting	Establish repository review procedures, solicit reports. Establish case story reporting
Links	Research and annotate related links inventory
Forum	Establish a discussion topic schedule, implement guided forums

REPOSITORY DEVELOPMENT

Network	Apply mentorship procedures, member to member contact access and policies
News	Community researcher profiles, methods, editorials
Tools	Implement "tool sharing" procedures
Skills	Implement "ask the researcher" online query/ Solicit tutorial proposals
Reporting	Implement repository access, evaluate review procedures
Links	Develop affiliate link agreements
Forum	Establish separate "interest group" forums / Site Evaluation

TUTORIALS ONLINE

Network	Expand International, Regional Networks
News	Community researcher international profiles
Tools	Increase tool Inventory, evaluate tool sharing procedures/ solicit software templates
Skills	Implement tutorials, solicit inventory
Reporting	Develop international reporting systems, conduct meta analysis of 1 st year
Links	Develop Global Regional Chapters
Forum	Conduct online debate

TOOLS & TEMPLATES

Network	Solicit Online Conference participants
News	Establish searchable database
Tools	Implement software download
Skills	Focus on research software
Reporting	Implement International Repository
Links	Software affiliates
Forum	Conduct online conference

Appendix

Web Survey Results

Key Informant Interview Summary

Advisory Meeting Summary