Pacific AIDS Network

Looking Forward, Standing Together: A Provincial Strategy for Community-Based Research in BC

Workshop Report

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PAN

<u>Vision</u>

PAN takes leadership on behalf of its members to create a future where member organizations are making demonstrable and consistent progress in ending the HIV and HCV co-infection epidemics and persons living with HIV/AIDS have improved health outcomes, and choices and freedoms to equally participate in society.

<u>Mission</u>

PAN is a vibrant, proactive member-based coalition that provides a network to support abilities and efforts or its member organizations to respond to HIV and HCV co-infection in British Columbia. PAN does this by facilitating communication between member agencies and persons living with HIV/AIDS (PHAs), including face-to-face networking opportunities, opportunities for mutual support; education and skills development; and undertaking collective action to influence public perceptions and policies affecting PHAs.

Introduction

Community-based research (CBR) is increasingly identified by government funders, academic researchers, AIDS service and community-based organizations and other stakeholders as a key pillar in the fight against HIV/AIDS. PAN and its member organizations recognize the need for CBR approaches which will result in interventions that improve health and reduce the spread of HIV. Unlike conventional research practices which give primacy to expert knowledge, CBR approaches explicitly recognize the wealth of knowledge found among people living with HIV (PHAs) and ASOs. Moreover, CBR emphasizes the importance of community-based responses to the epidemic and the critical contributions of front-line service providers. By working collectively and abiding the principles of CBR, researchers and community can assure the development of the critical mass required to:

1) Encourage rigorous and innovative population health and health service research

2) Understand and demonstrate the benefit of cross-cutting approaches to delivering health and community services

3) Influence policy and practice

While a number of community organizations in British Columbia have responded enthusiastically to the growing momentum for CBR projects, there are still a number of questions and concerns regarding the ability of CBR to fulfill its promises of equal partnership and social change. As a province, British Columbia is marked by tremendous geographic and socio-cultural diversity. Furthermore, AIDS service and other allied organizations have varying levels of capacity and resources with respect to their ability and desire to participate in CBR.

In response to these concerns, PAN organized a one-day CIHR-funded workshop entitled *Looking Forward, Standing Together: A Provincial Strategy for Community-Based Research in BC* which brought together community-based organizations, people

living with HIV (PHAs), academic partners and other stakeholders. The aim of this workshop was to bring these stakeholders together to build capacity around CBR and develop a strategic vision for CBR in the province that recognizes the unique strengths and challenges of this diverse province.

PAN's Role in CBR

PAN has pursued an increasing level of activity with regard to CBR and knowledge translation and exchange in the province, including organizing a provincial stakeholder team for the *Positive Living, Positive Homes Research Project*. PAN is involved with numerous other CBR studies in various capacities, including the *Impact of Food Security on Health Outcomes in People Living with HIV/AIDS Across Canada Study* and *Canadian HIV Women's Sexual and Reproductive Cohort Study*, and currently organizes a Quarterly Knowledge Exchange Meeting between CBR practitioners to discuss ongoing methodological issues and knowledge gaps in the province. In July 2011, PAN, in partnership with CIHR Centre for REACH, created the position of Community-Based Research Manager to further promote research partnerships between PAN member agencies and academic researchers.

Background to the Workshop

On September 13, 2011, PAN held a one-day workshop entitled *Looking Forward, Standing Together: A Provincial Strategy for Community-Based Research in BC* in Richmond, BC as part of its Annual General Meeting. The goal of this event was to bring together representatives from PAN member organizations, PHAs, academic researchers, funders and other key stakeholders in a collaborative and mutually respectful environment to create a collective vision for the direction of HIV-related community-based research in the province and provide a medium in which new relationships could develop. In total, over 75 participants attended this event.

The overall goal of this project was to advance CBR in BC. The specific objectives of the one day Workshop were to:

1) Build on the momentum that currently exists regarding a number of CBR initiatives in BC and promote the creation of sustainable relationships across community-based organizations, researchers and academics, PHAs and related stakeholders including within public health.

2) Provide an information update to all 50 PAN member organizations and their PHA delegates, along with related stakeholders regarding the Food Security and Housing CBR initiatives; as well as an understanding as to how these initiatives relate to work that it is being done nationally by the CIHR Centre for REACH and other national partners.

3) Develop knowledge exchange for all 50 PAN member organizations & key stakeholders on the community-based research framework and approach and its current role in BC today including the above-mentioned research projects PAN is a partner.

4) To create a BC CBR Strategic Roadmap which will identify potential next steps with regards to building CBR networks in BC including issue and priority identification.

The workshop schedule included presentations by Dr. Sean Rourke (Ontario HIV Treatment Network and Centre for REACH) and by Dr. Charlotte Reading (University of Victoria). Dr. Rourke's presentation shed light on the process of CBR and how it differs from traditional clinical research and some of the tangible achievements of CBR projects across Canada. Dr. Reading's presentation spoke to the decolonization of research in Aboriginal communities through CBR and raised a number of fascinating ethical questions.

The workshop also included two panel sessions. The first session feature Ben Stevenson (Project Coordinator for the *Impact of Food Security on Health Outcomes in People Living with HIV/AIDS Across Canada* project) and peer researchers Hesham Ali, Andrew Beckerman, Kecia Larkin, Chuck Osborn, Val Nicholson and Dale Northcott. This panel provided the audience with insight into the benefits and challenges of working as a peer researcher on a CBR project and spoke to the unique and invaluable experience and expertise they bring to research projects. The second panel, entitle Current CBR Scene in BC, featured Dr. Brian Chittock (AIDS Vancouver), Terry Howard (CIHR Community-Based Research Facilitator for BC), Dr. Angela Kaida (Simon Fraser University), and Heidi Standeven (PAN), and provided updates on the various projects they are working on as well as insight into CBR from their diverse perspectives.

A third key component of this workshop was interactive small group discussion sessions in which teams of approximately 3-6 people explored pertinent questions related to the direction of community-based research in British Columbia. Eight of the questions were generated from a small sample phone survey of PAN member agencies in the weeks leading to the workshop. A ninth question was generated by workshop participants. Each group brainstormed action-based solutions to the questions in a World Café-style format. The responses were subsequently presented back to the entire workshop audience.

Core Themes

Relationship Building

Relationship building was among the most significant and pervasive themes of this workshop. Strong relationships between community and academic partners are key to successful research partnerships, which must be in place before research projects can be initiated. Presentations, panels and discussion groups all emphasized the importance

of genuine relationships of trust and respect that can sustain the long-term commitments that CBR projects require.

> ➤ "People have to understand that there are governing authorities in place, through which researchers have to gain relationships with to gain access [to the community]. Respect these governing agencies."

> ➤ "It's the way it`s being done, and the way it needs to be done. It is an art form; it all comes down to relationships. If you can connect the right people, you can have profound things happen."

> ➤ "I want to emphasize that personal connection. We're all invested in this together."

Stigma

Stigma remains one of the main barriers to research and manifests in numerous forms. Stigma inhibits many people living with HIV from participating in research opportunities, particularly in rural and remote regions and in cases where there is a strong desire to not disclose one's sero-positive status. Community-based research projects must also be cautious to not inadvertently reinforce stigma by framing questions in ways that are culturally or otherwise insensitive.

> ➤ "We need to break down barriers and stigma"

> ➤ "Biggest barrier is stigma. How do you overcome it? People are more likely [to participate] if questions are meaningful and authentic."

> ➤ "Stigma keeps people isolated and inaccessible to researchers."

Accessibility of Results

Trust, one of the essential components of strong relationships, can be weakened at the end of research projects if the end results of the project are not accessible or useful to community partners. The importance of accessible research findings was a

prominent theme during the workshop. In particular, the desire for more creative and arts-based forms of knowledge translation and exchange was highlighted.

> ➢ "Results need to be shared going both ways and being accessible."

> ➢ "Create events where community can generate new data - create a sense of play with it. HIV Edmonton had an art show and bath house. We talked about small businesses… how to re-define a report, make language plain and accessible. The data should be colourful and dynamic."

One Size Does Not Fit All

Participants in this workshop came with varying backgrounds and experience with community-based research. Researchers need to be prepared to engage with different methodologies and processes, depending on the communities they are working with. In some instances, community partners will have to capacity and desire to participate in large-scale, time-intensive projects. In other cases, community groups may need smaller-scale research that addresses very specific topical issues of interest.

> ➢ "Acknowledging that maybe one size doesn't fit all – one piece of research isn't going to fit everybody."

Empowerment

This workshop highlighted the many ways in which community-based research that respects PHAs and community-organizations as equal partners can contribute to genuine empowerment for everyone. Tangible skills development is one key element of this empowerment. Also, the research process itself can also be a validating and empowering experience, particularly when peer researchers are employed. Furthermore, for many participants, research interviews provide an opportunity to tell their life stories and contribute to a larger social good.

➢ "These people [peer researchers] have big hearts, compassionate, I've never had an interview that's lasted 3 hour and I've learned a lot about myself. I can't wait for the report. It is a major step."

➢ "I am very honoured to be involved in this study. The work we're doing is exciting, the ASOs are partnered in this. The work that they're doing in the front lines is so important for community research. They are our ambassadors, it's really positive, they are our leaders now and for the future."

➢ "I've been a peer researcher and it's amazing, things you learn about yourself, and others that you don't expect. The camaraderie, the support, to the academia colleagues, that support."

Group Discussions

Group 1

What is community? How do we define it in the research process? Are non-governmental organizations and ASOs the target population of CBR projects or are they gatekeepers to other community members?

This group emphasized that each individual belongs to multiple communities, which are often overlapping. Community begins with the self and expands outward to include family, friends, work, and those who take care of each other. While formal organizations and geographic clusters are recognized as communities, this group emphasized that relationships, and the responsibility to take care of one another, are the core defining features of communities.

In the context of CBR projects community can be defined as the diverse actors who come together with a common goal. This includes the academic and community representatives on the research team, as well as the wider population from whom the

data is collected and anyone who will be impacted by the results. It is therefore necessary to establish clear goals of a research project in the earliest stages of partnership.

ASOs, which often constitute the official 'community partner' in CBR projects, are important gatekeepers of information and can act as a bridge with respect to connecting academics with PHAs and disseminating information at a grassroots level. However, this group emphasized that PHAs – particularly peer research assistants (PRAs) also play an invaluable role in reaching other PHAs who are not affiliated with ASOs, and are often effective vectors of communication and knowledge dissemination.

In order to move forward in the development of effective and sustainable research partnerships, this group identified respect as the number one issue. Respect needs to flow in multiple directions. In addition, there is a need to address stigma within the research community itself in order for the capacity and knowledge of PHAs to be more fully respected in the process.

Group 2

How do we engage smaller, capacity and resource-limited organizations in research partnerships?

In response to this question, this group recognized the importance of clear and honest discussions in the early stages of the research process regarding the capacity levels and strategic mandates of small organizations. Research partners need to be cognizant of the infrastructural and transportation challenges of northern and rural organizations and take these into consideration in the research design.

Smaller and remote organizations face the additional challenge of not being well connected to research partners and opportunities. As a result, they tend to miss out on

participating in projects that may be of direct interest to them and their practices. This group identified the role of PAN and other larger organizations in facilitating research contacts.

Smaller organizations may prefer to be initially incorporated into research projects as knowledge users rather co-investigators in order to build their research vocabularies and capacity. There also needs to be clearly articulated benefits for community organizations to encourage their participation. This group also suggested that more research-related training opportunities are needed to help organizations identify their own research questions.

Group 3

How can we better incorporate the GIPA principles into community-based research projects to meaningfully engage people living with HIV/AIDS and/or co-infected with HIV/HCV and/or 'at risk' and ensure their sense of ownership in the research process?

This group came up with numerous suggestions for authentically engaging PHAs in research, many of which are directly tied to overcoming stigma. One highlighted suggestion is the need for research questions to be meaningful to their lives and provide an empowering opportunity for participants to tell their own stories. To do this, researchers need to develop relationships with their target populations prior to developing the research tools.

The practice of using peer researchers was highlighted as an existing success of CBR projects. Other suggestions include incorporating knowledge translation activities throughout the data collection stage in order to help participants understand the impacts of their contributions. Researchers need to remove barriers with regard to language, literacy, and location.

<u>Group 4</u>

Trust is often considered the key to a successful community-based research project. How do we develop and maintain trust between PHAs, community organizations, academic researchers and other stakeholders throughout the entire research project?

Mutual trust between researchers and community partners, according to this group emerges from accessibility and transparency at all stages of the process. Respecting confidentiality and diversity are also key building blocks of trust.

This group suggested that trust between various stakeholders can be greatly improved by a willingness to lose one's own perspective and empathize with another person's viewpoint. Questions being asked of participants must be thoughtful, considered, and justified. Mechanisms need to be in place to assist participants and peer researchers with navigating questions that are potentially triggering (i.e. questions that probe into participants' histories of sexual and other forms of violence, substance abuse, and so forth). Additionally, consistent engagement with the community, regular updates on the project status, and the translation of results into accessible information can improve trust between partners.

<u>Group 5</u>

How do we improve knowledge translation and exchange? What is the best way to communicate findings to study participants and community members and balance that with other stakeholders' needs?

This group provided numerous strategies and concrete examples of effective knowledge exchange strategies, all of which highlighted accessibility and creativity. Knowledge exchange activities that allow community members to easily self-locate within the findings, as with the use of narrative stories and anecdotes, are particularly empowering.

Creative and art-based events like plays and photography exhibits in community forums, and social media are effective tools for disseminating information in a language that is accessible to the community. Researchers using traditional reports and presentations to disseminate findings should aim to make them as dynamic as possible through accessible language and easy to read, colourful graphs.

This group made the observation that when community members understand the research results in a deeply personal way and actively participate in its dissemination, there is likely to be a ripple effect in which the information is continually reproduced long after the study is officially concluded.

Group 6

There are multiple priority action outcomes for community-based research projects (e.g., policy change, increased knowledge, increased public attention and awareness of key issues, changes to service delivery, etc.) How do we ensure competing priorities of various team members and stakeholders are managed and balanced in the research process?

This group came to a very straight-forward conclusion in response to the question: all action outcomes identified by the research team are legitimate and important. Multiple priority outcomes should be complementary and manageable if there is clear communication early in the research process. The research design must reflect the various aims of the project.

<u>Group 7</u>

What are the challenges of conducting community-based research in a province as geographically, culturally and demographically diverse as BC? What research and knowledge translation strategies are needed to ensure inclusivity?

This group noted that organizations servicing geographically and culturally isolated communities are often faced with more complex challenges and increased stigma with respect to providing services to PHAs. They tend to have limited capacity and connectivity to potential research partners. As a result, they may miss out on beneficial research opportunities. This group highlighted transportation challenges as one of the key difficulties of including diverse communities in research projects, and as an important issue for researchers to be cognizant of early in the research design.

Noting that 'one size does not fit all', this group highlighted the need for smaller, targeted research projects that focus on specific communities. There also needs to be efforts to connect communities and organizations that do not have the capacity to engage in research with study findings that may be of use to them. In particular, this group suggested that a database of studies addressing service delivery in remote regions and with diverse communities would be an effective tool for disseminating knowledge throughout the province.

<u>Group 8</u>

What should PAN's role be in furthering community-based research in BC?

This group provided a very straightforward and comprehensive list of priorities for PAN's role in furthering community-based research in the province, first among which is ensuring that the community voice is protected within CBR studies. This group expressed a desire for PAN to take on a provincial leadership role with respect to

identifying relevant research questions and disseminating findings. Another key desire is for PAN to advocate for a grassroots approach to CBR in which community organizations can play a stronger role in directing research. In particularly, this group expressed a need for PAN to assist with capacity building in areas such as grant-writing.

Group 9

What is the relationship (potential) between the CBR and community activism?
How might they sponsor one another?

This particular question was generated by a group of workshop participants who desired to explore the links between community-based research and activism. This group noted that the shared histories of boundary-pushing, intellectual equality and commitment to social justice of community activists and community-based researchers provide an essential foundation for partnership. The opportunities for reciprocal learning were emphasized: while community activists can use research findings to bolster social change, academic partners can and should learn as much as possible about the community's needs, interests, and strategies for mobilization. The notion of 'shared vulnerability' was also emphasized. This notion refers to the fact that it cannot only be participants who accept the risks associated with research. Researchers must also be willing to step outside their comfort zones and speak openly about social injustices within activist and policy circles.

Moving Forward

This workshop provided an excellent opportunity to collectively identify and address the existing strengths and needs for the future with respect to community-based research in BC.

Existing Strengths

The many strengths and existing capacities of community-based research in BC were frequently recognized throughout the day:

1) *Strong Partnerships*

   One of the most prevalent strengths evidenced in the workshop is the strength of partnerships across sectors. Community and academic partners are well linked through the CBR in BC Quarterly meetings, and through existing research projects. A number of CBR projects in BC are connected across Canada to other community-based organizations and stakeholders. These existing networks provide an excellent resource for developing research collaborations and undertaking province-wide CBR projects.

2) *Greater Involvement of People Living with HIV/AIDS (GIPA)*

   The GIPA Principles are strongly recognized throughout PAN member agencies and academic partnerships. In particular, the use of peer research assistants in a number of projects speaks to the integration of GIPA Principles into CBR. The impressive efforts of peer research assistants to develop research skills, carry out data collection for numerous projects, and connect researchers with a wide network of other PHAs as study participants were one of the key highlights of the workshop. As one the peer researchers articulated: "We all took this on because we could see a need for a voice to be heard that wasn't being heard. We're allowing it to be heard, and scream and make positive changes."

3) *Connectivity*

Community-based research projects in BC have resulted in the unexpected yet welcome benefit of increasing connectivity between peer researchers, PHAs and AIDS service and other community-based organizations. CBR practitioners have noted that peer researchers are serving as an important vector of information about programs and services beyond the scope of the study. Many peer researchers are already active within their respective communities, and their participation in CBR is providing an additional platform to carry-out this community development and activist work. As one peer researcher expressed, "each of us is impassioned to do the work in our communities; [working as peer researchers] gives us a broader way of doing the work".

4) *Needs Identification*

The capacity of community-based organizations and frontline service providers to articulate research needs and areas of interest represents one of the biggest strengths among CBR practitioners in BC. This capacity was amply demonstrated during the workshop, wherein participants raised a number of knowledge gaps. These issues include identifying and combating pervasive forms of stigma, and addressing growing concerns around HIV and aging, among others.

<u>Future Directions</u>

In addition to these existing strengths, the workshop provided an opportunity to identify priority areas for the future direction of community-based research:

1) *Earlier and More Comprehensive Relationship Building*

Research projects provide many opportunities to develop networks and build relationships throughout their lifecycles. However, a key direction for future research projects identified in this workshop is the desire for more relationship building activities between academics and community partners in the early stages of CBR studies. Strong relationships of mutual trust and respect, which are

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foundational to successful research partnerships, take a considerable amount of time to establish. By making relationship building the first step in any CBR project, great trust and more meaningful research questions and methodologies can be established. Examples of early relationship building activities include site visits by the investigative team to various communities and organizations involved in the study and community needs-identification workshops before research questions are generated.

2) *Mutual Capacity Building*

The concept of mutual capacity building refers to need to expand from the conventional notion of capacity building as training community members to partake in research projects. Currently, there are excellent capacity building activities for peer research assistants and community-based investigators to learn skills such as grant-writing and focus group moderation, directly resulting from CBR projects. However, there is a widely recognized need to build the capacity of academic partners to communicate and work within the culture of community-based organizations. Future capacity building activities, particularly those occurring at a provincial level, should reflect the notion of capacity-building as a two-way street.

3) *More Creativity*

British Columbia's diverse geographic and cultural landscape was an omnipresent theme at this workshop. A key message emerging from this diversity is the need for moving beyond a 'one-size-fits-all' approach to community-based research. With respect to this abundant diversity, more creative methods for encouraging and enabling participation and for exchanging knowledge are necessary.

4) *Greater Accessibility of Research Results*

Translating research findings into accessible, actionable messages is essential to ensuring CBR projects fulfill their mission of contributing to positive social change. However, it is equally a crucial step toward generating community support for further research opportunities. Providing communities with tangible evidence of the benefits of research and status updates on the findings throughout all stages of the projects can encourage stronger relationships. Creative methods of knowledge translation should be encouraged in order to communicate effectively with as wide an audience as possible. Community partners also desire a greater role in knowledge translation and exchange activities, and should be seen as valuable resource for disseminating research findings in contextually relevant long after a CBR project is decommissioned.

Evaluation Results

Two evaluation methods were utilized to collect feedback on the relevance and effectiveness of the workshop. Following the workshop, an evaluation questionnaire was distributed to collect quantifiable information on capacity-levels of the participants with respect to community-based research pre- and post-workshop. Qualitative information was also sought through the free comment section of the evaluation forms, and through an external evaluation consultant who conducted interviews with a small sample of workshop participants throughout the PAN conference.

<u>Evaluation Questionnaires</u>

Answers to each question were rated on a Likert-scale: Poor (=1), Fair (=2), Good (=3), Excellent (=4). The averages for each response are presented below. These averages are also presented in percentages to highlight the increases from pre- to post-workshop, such levels of confidence and desire to participate in community-based research. The questions were designed to capture the impacts of the workshop on CBR

capacity and understanding among the participants. In total, 33 questionnaires were completed.

Figure 1. Evaluation Results

Question	Before	After	% Change
1) Your understanding of the potential benefits of community-based research for AIDS service and allied organizations	2.63 (65.75%)	3.48 (87%)	+21.25
2) Your knowledge of current HIV/AIDS-related community-based research projects and stakeholders in British Columbia	2.38 (59.5%)	3.23 (80.75%)	+21.25
3) Your knowledge of opportunities to get involved in community-based research	2.34 (58.5%)	3.16 (79%)	+20.5
4) Your confidence to participate in community-based research	2.48 (62%)	3.16 (79%)	+17
5) Your desire to participate in community-based research	2.77 (69.25%)	3.56 (89%)	+19.75
6) Your confidence to build relationships and partnerships with other community-based organizations, academics and other researchers	2.73 (68.25%)	3.34 (83.5%)	+15.25

As evidenced by this table, the average 'before' responses to each question fell within the Fair to Good range. Following the conference, there was a marked increase in each question, resulting in averages in the Good to Excellent range.

Qualitative Comments and Reflections

The following is selection of written and oral reflections by participants on their experience at the workshop:

➢ "The CBR was very relevant. I would like to see research on HCV and Hep B"

➢ "CBR was interesting in that it gave a national perspective"

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➢ "CBR-interested but applying for funds is daunting, not clear about the process to obtain funding. I don't have the confidence to put a proposal together myself. However, I have made contacts to get support"

➢ "Definitely learned lots about CBR. I'm going to hook into REACH"

➢ "There had been concerns about support for the PRAs in the project and the CBR session resolved those concerns"

➢ "I didn't know much about CBR and I now know I need to learn about the process for developing a project"

➢ "The CBR session highly relevant"

➢ "The CBR project (longitudinal study on women's health) info was really useful. I can take it back to women in [my community]"

➢ "The presentation made by Sean Rourke [was most useful to me]. I was interested in how the monies were rolled out"

➢ "The CBR panel was moving & educating. It gave me courage and confidence"

➢ "This is building my gap in so many different aspects on so many different topics. I need time and energy to pay attention and be able to dissect every different topic"

➢ "I absolutely learned more about CBR & the process & how it could benefit. I'm still hesitant on my capability of putting a proposal request forward & the process it takes. However, I now have people I can help for further clarification"

➢ "I have looked over funding proposals & found it interesting but need more info to be part of the movement"

➢ "The final speaker: Aboriginal CBR was exceptional! Hard hitting, honesty, balanced with sensitivity, humor & passion"

➢ "I am interested in CBR but feel I don't know enough to be putting in a grant proposal. I find it interesting & would like more info"

Moving Forward

In light of the success of our 2011 workshop, PAN is intending to follow up with a second workshop in 2012 to address some of the issues of interest identified in this report. PAN's Community-Based Research Manager will continue to facilitate opportunities for PAN members to engage with community-based research projects and increase capacity. PAN's website now features a sub-section devoted to CBR, and includes number of resources such as glossary of research terms and a checklist to help community-based organizations navigate research partnerships. In addition, the CBR Manager will continue to coordinate the CBR in BC Quarterly meetings, which are a series of meetings that bring together research stakeholders from community, academia and government to address topical and methodological issues in the province. The CBR manager will also support future knowledge translation and exchange efforts for ongoing research projects.

Acknowledgements

For any questions regarding this report or for more information on community-based research in BC, please contact:

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