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# Peer Worker Support Project

**Developing Industry Support Standards  
for Peer Workers Living with HIV**

**Terry Howard**

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# Peer Worker Supports Project

The need for an industry standard of support tools when employing people living with HIV has come directly from the community members themselves. Peer workers; including research associates, health system navigators, counsellors, and other peer workers who choose employment to suit their personal circumstances have voiced their concerns on the inadequacies of predominantly social-work-adapted support systems that don't meet their needs as workers. Some existing supports need merely to be modified further to accommodate the needs of peer workers, others need to be created expressly and utilized systemically on new and existing research and program based projects.

This project is the genesis of the creation of a “living” document that will provide support options for peer workers and those who employ them. This document will be updated regularly with new options as they become available, and offered in the form of an open-access digital toolkit.



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# Peer Worker Support Project: Data Collection

## Rationale And Objectives

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1. **Background**
2. **Methodology**
3. **Findings**
4. **Recommendations**
5. **Next Steps**

## Focus Groups

The initial plan for this project was to schedule two focus groups, one for peer workers, and one for researchers/health care providers. The focus groups provided a guided discussion forum to explore what supports are currently in use, any gaps in those supports, and what kinds of additional supports are needed. We drew upon existing support tools that could potentially be adapted to more appropriately support peer workers living with HIV working a community organization, and/or on a research project. Many existing supports have proven inadequate, or poorly utilized by peer workers to the point of non-functionality.

Focus groups were intended to be the starting place to gather information for the development of industry support standards in the form of a “tool kit” where new research teams or project directors can select support tools that fit their specific needs while becoming aware of the basic support requirements for peer workers living with HIV on any project/program. Once developed, this tool kit will remain a work in progress and will be regularly updated as peer worker support needs change and evolve. It is intended that eventual wide spread industry use and input from those who utilize the toolkit will organically promote its utility as the industry standard when developing projects employing people living with HIV.



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# Background

The need for an industry standard of support tools when employing people living with HIV has come directly from the HIV community.

The need for an industry standard of support tools when employing people from the target community has come directly from the members themselves. Peer workers; including peer research associates, peer health system navigators, peer counselors, and other peer workers who choose employment to suit their personal circumstances have voiced their concerns on the inadequacies of predominantly social-work-adapted support systems that don't meet their needs as workers. Some existing supports need merely to be modified further to accommodate the needs of peer workers, others need to be created expressly and utilized systemically on new and existing research and program based projects. The following quote is from a peer research associate coordinator and illustrates their thoughts on the need for industry standards for peer workers.

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*From my somewhat limited experience supporting peer researchers, I can say that the biggest thing I was able to provide was authentic empathic engagement. I was always there for the researchers when they needed to debrief, hear their concerns and*

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*help facilitate getting their needs met or further bolstering the supportive environment they were working in (e.g. through talking to community organization staff or research investigators to provide additional resources (time, money or personnel) to help the peer through the situation). I made a concerted effort to do this too - I didn't just wait for peers to come to me with 'problems'.*

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*We had lots of personal one-on-one conversations to make sure peers had safe channels to express their views as well as group conversations to facilitate peer team building, awareness building and solidarity.*

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*I always made sure to emphasize that peers took seriously the practice of 'self-care' and always tried to assist or accommodate them in this regard, sometimes to the delay of crucial research deadlines, but for the benefit of the peer's health.*

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*One of the biggest problems I faced though was in hiring peers who were perhaps not ready for the job at hand and who faced continual psychological interpersonal or community-level barriers to full involvement with the work we were doing. Whether the case was having a peer not fully managing their drug addiction, not having fully processed the stigma and trauma of sero-converting amongst a First Nations community who were not understanding, or who had concurrent illnesses that were just too debilitating to prioritize the work at hand, these were instances where few supports would have prevented a 'crash and burn' scenario. It was more a case of not hiring the right person for the job, although in*



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*some communities, there are so few candidates among those living with HIV to be peer workers, that we had to do the best we could with hiring.*

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*To help structure this on-going conversation, I'd like to throw an idea out there that we outline a continuum of supports necessary for peers at different levels of 'work-readiness', stratified by different levels of work intensity and scope (i.e. part time, contract work, professional full time), current obstacles being faced, and gaps that we hope to fill with newly designed support systems for HIV peer workers.*

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*One of the support concepts I'd be interested in pursuing too is how to facilitate better self-care practices among peer workers. This is not to 'off-load' the issue from practitioners and researchers on to peers, but rather to be explicit about the fundamental limitations we face with lack of resources or strict institutional working environments.*

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*Some studies suggest that finding 'meaning' in one's situation is a crucial step to being ready for self-care with chronic illnesses or experienced stigma/oppression/loss. In this regard, I might connect self-care to the authentic empathy piece I was talking about earlier, and suggest that one great way of supporting peers is by making their work meaningful (MIPA obviously fits here) which is either done through, a.) providing more participatory avenues in decision-making or analysis, b.) tailoring work relationships to the individual and c.) connecting with people on a 'personal level' to*

*find where their values lie in whatever peer work they're doing (although maintaining boundaries becomes here) and d.) acknowledging how much emotion and feeling goes into and comes with this work.*

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# Methodology

## Focus Group for Peer Workers

The first focus group held in Vancouver was directly with peer workers themselves to provide a forum for their thoughts and experience with support provision. After introducing the topic of discussion, the peer workers were asked about what supports worked well, where there were gaps, and what services exist, but need to be adapted to become more appropriate in order to support peer workers.

Analysis of the discussion immediately revealed major themes that fit the feedback given by peer workers. These are as follows:

- **Physical Supports-** issues of physical stress, personal safety
- **Psychosocial/Self Care Supports-** role clarification and boundaries, HIV disclosure, burnout, secondary traumatic stress, substance use, depression and mental/emotional health issues
- **Cognitive/Educational Supports-** changes in peer and collegial relationships, think-tank model, best/wise practice models
- **Service/Project Delivery (Institutional) Supports-** tokenism, job security, progressive employment opportunities
- **Financial Supports-** form of compensation, accommodating disability pensions



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- **Role Models/Mentors**- individual/group support, debriefing format, sharing circle, future job opportunities

### **Focus Group for Researchers/Service Providers**

The second focus group held in Vancouver was with a group of Community Based Organization decision-makers, and with Institutional and Independent Researchers that engage with peer workers on their projects.

They were provided with a summary of the feedback from the peer workers, and asked to comment on the stated issues from their perspective.

By gathering input and perspective from both groups - support consumers and support providers - it was possible to construct some suggestions for appropriate support provision that fulfills the needs of HIV peer workers. It is worth noting that, no single support theme or tool fit every peer worker's needs. Each project team must discuss individual requirements for their specific project considering their peer workers, and develop and utilize tools fitting the work, and the workers engaged on their project.

It is hoped that HIV industry support standards will rise organically with examples from successful projects that provide best/wise practice supports for their peer workers.

### **Cafe Scientifique with HIV community**

The next step was to present the findings from the two focus groups to the larger HIV community to promote inclusivity from those not currently engaged in HIV work, and researchers/service providers that were not part of the focus group discussion. We asked for their feedback and thoughts on what was presented, and asked what kind of peer worker support tools would they consider using on future projects.

## **Findings**

Section 2 contains a detailed description of the analysis of both Focus Group's and Cafe participants' feedback, categorized by theme.

- Detailed Peer Worker feedback analysis
- Detailed Researcher/Provider feedback analysis
- Detailed Cafe Scientifique feedback analysis

The analysis in Section 2 contains both a summary of the focus group discussion in many cases, and direct quotes from participants to give context and authenticity to the analysis process.



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# Recommendations

Through increased awareness of best/wise practices of peer worker supports endorsed and utilized by successful projects in Canada, it is hoped that HIV industry support standards will rise significantly to meaningful levels for people living with HIV who choose to be engaged in work within the HIV community.

This report is intended to be a “living document” to provide suggestions for peer worker support tools that have been proven effective and/or appropriate on successful projects in Canada. By offering a description of support tools, and a brief explanation of how and why they work, we encourage project teams to consider adopting the offered tools during the development phase that are relevant to their project. As additional support tools are identified, we will incorporate them into the inventory of suggested support tools available for review in this report.

Why are these findings significant? The focus group findings are an excellent example of GIPA/MEPA principles in practice. By including the voice of peer workers and those affected, as we create an open access document for all suggested support tools, and by creating an iterative, “living document” to be updated as required when new practice or tools become available, we provide strong evidence of the meaningful engagement of people living with HIV/AIDS.

## Next Steps

The data presented here will be used to develop and assemble a series of digital “tools” for support that have been successfully employed by projects employing peer workers. All of the work will remain “open access” and available to any who would like to make use of the suggestions and options for support provision. The tools will be added to, and updated as new information comes available from the peer worker community.

The focus group findings and subsequent additional support data collection will be actively disseminated to the relevant communities (peers, greater HIV community, researchers, service providers, funders like CIHR) for review and uptake in existing projects.

I encourage all readers to review these gathered suggestions and encourage implementation of the findings that are pertinent to existing projects. Feedback and additional support provision ideas are most welcome!

The principal hope is that peer worker support tools should organically become industry standards as a basic level of support provision, and to be included for budgetary consideration in



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new projects. Suggestions for support provision implementation via the “tool kit” offerings could become standard practice on creating research projects and service provision utilizing peer workers living with HIV.

Thanks for your kind attention.

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Please also see: <http://bchivcbr.org> for further information on CBR and Peer Workers



# Focus Group Feedback Analysis

## Themes

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1. Physical
2. Psychosocial/Emotional
3. Cognitive/Educational
4. Service/Project Delivery
5. Role Models/Mentors
6. Financial

## Themes

The information gathered during the Focus Groups was coded under the following general themes to capture various issues that were described by the participants. Information from the Cafe Scientifique has been incorporated into the Focus Groups analysis under the appropriate themes.

### 1. Physical

The discussion around physical aspects of support tools fell under two main areas of discussion- Worker Identification issues, and Safety issues.

#### **Worker Identification:**

Many peer workers suggested that identification badges were a double-edged sword. By wearing a badge with the title “Peer Research Associate” or “Peer Worker”, they not only outed themselves and promoted questions around what “peer” meant, but also inadvertently outed the participant or client when they were meeting in a facility that required them to identify the reason for their visit and the client they wished to see to building security staff or reception area. On the other hand, most felt it was necessary and desirable to wear some form of “official” or



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“sanctioned” identification to provide credibility and a level of professionalism when visiting facilities that required them to state their reason for seeing a participant/client. The suggested solution was to develop and provide a generalized identification badge on the role of the peer worker, and the organization leading the work that would not unintentionally breach the confidentiality of the participant/client.

### **Safety:**

Discussion about safety was from both a personal and professional perspective. Personal safety in the form of physical protection for peer workers, and professional safety in the form of boundary-setting, administrative protocol and procedural guidelines minimizing the liability of the research team and/or partner organizations employing peer workers.

Physical hazards of potential outreach worksites should be assessed prior to sending in peer workers, and ongoing assessment should be maintained as the work proceeds in order to accommodate changes in the environment. For example, offsite visits to neighbourhoods where participants/clients reside, should be assessed for potential hazards and pro-actively addressed before the work begins and then monitored throughout the work. Peer workers also underscored the importance of their feedback from participant/clients stating that “meeting with people where they are” was extremely significant and often

would not provide accessibility to vulnerable populations without this accommodation.

Focus group participants suggested that in addition to procedural guidelines, items like cell phones, pagers, and walkie-talkies were helpful ways for peer workers to maintain contact while in the field.

By providing suggestions for healthy guidelines, and alternative methods of worker support, we engage peer workers in the process of more adequately determining and assessing the physical risks of outreach worksites and mitigate the potential hazards of accommodating meeting participant/clients where they are.

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*“You need to provide healthy guidelines and alternate peer support for those workers working particularly in high risk neighborhoods...’without these supports I would be hooped’... “*

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## **2. Psychosocial/Emotional**

As with Safety, discussion on Psychosocial/Emotional support challenges included both personal and professional aspects of the issue. Due to the fact that many peer workers are service recipients of the organization that employs them, there are numerous challenges dealing with the dichotomy of being both a



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worker and participant at the worksite. Many have prior social relationships with the participants of the project undertaken. Many have prior client/service provider relationships with members of the project team who hire them. The challenges are present in navigating the transition from service recipient to staff member, dealing with the overlap as a service recipient and client, and establishing healthy professional and personal boundaries for this new role.

Once hired, peer workers described how they had been told by their new employer to seek out their support/care in another setting with another organization to alleviate the potential of conflict. While this may solve the problem of conflict, it creates a care and support problem for the peer worker who may not be able to find appropriate care elsewhere due to geographic, gender, transportation, or quality of service provision issues, and need to be carefully considered.

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*“It takes time to get used to changing hats, from volunteer to client, or from worker to member, or client to worker. It requires time and practice and a certain degree of flexibility and discomfort at times, boundary issues arise, training and ongoing check in/debrief can mitigate some of the tensions and conflicts in this work.”*

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### **Boundaries:**

Training peer workers how to establish healthy professional and personal boundaries is a complicated process that takes considerable time both initially upon hiring, and ongoing throughout the life of the project. It is well advised to monitor the utility of boundary setting tools as work progresses. Awareness of potential boundary issues inherent to the workplace, selection of peer workers, and the nature of the work, i.e. data collection with vulnerable populations, is key to creating the right environment to deal with boundary issues as they arise. The goal is to develop tools that will allow the peer worker to identify and successfully deal with challenges to their personal and professional boundaries through empowerment and support for their decision making in the face of these challenges.

After training, the establishment of a scope of practice for the proposed work was suggested by the researcher/service provider focus group participants. Helpful tools to consider include: creating detailed job description(s), open discussion around worksite challenges, ongoing monitoring of boundary maintenance tools and their utility, regular feedback/support sessions specifically to deal with boundary issues in both one-on-one and group settings, and skilled observance and management of the ‘perfect peer’ phenomenon.



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*Often when peers take on new work in professional environment, they gain a lot of pride. They may have not have had meaningful work before, so this new job status contributes to the 'perfect peer' phenomenon.*

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The **perfect peer** typically tends to blur boundaries; work beyond their skill comfort level; appears to lack the ability to 'say no'; publicly often become 'the face of the project'; and generally has an unhealthy 'need to please' the project team beyond their scope of work. Successful management of this phenomenon includes identifying it in the initial stages, not putting the peer worker on a public pedestal to further the appearance of the project's commitment to the community, and supporting the peer worker's genuine desire to perform well with healthy acknowledgement of their work within the scope of practice.

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*Don't take it all on!! Learning how to say NO is an undervalued skill. It is essential to find a balance of life with HIV and outside of HIV...what is your scope of practice? What is my role? Scope of practice are key words!*

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In the majority of projects employing peer workers - research, health care support and access - the very nature of the ability of peers to provide access to community members creates an overlap in professional and personal boundaries. It is important to acknowledge that this is where a lot of peer work occurs, and is essential to the success of the project without encouraging

unhealthy behaviours. The key to successfully negotiating these boundary issues is through the development and provision of tools designed specifically by, and for, peer workers to empower them in their decision making process as challenges to their professional and personal boundaries are encountered. Support for this decision making, and post-event debriefing with the project team to retain awareness of current issues is recommended for the success of projects employing peer workers.

### **Support:**

Providing support for peer workers on a project is often comprised of conventional tools accessible to other workers who don't live with HIV. While it is important to draw on existing supports within the work environment available to all workers in an organization, it is also important to acknowledge and accommodate the specific needs of workers living with HIV who have been hired specifically as members of the HIV community.

Support is such a broad term, the focus group discussion was broken down into several pertinent areas to provide the opportunity to discuss support provision that worked, and areas that needed to be developed further to provide adequate and appropriate support for peer workers. These areas are described in more detail as follows:

- debriefing/clinical supervision



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- ‘triggers’, both emotional and physical
  - burnout
  - HIV disclosure and confidentiality issues

*Debriefing/Clinical supervision:*

Both focus groups discussed the importance of accessing existing supports within the project’s organization when possible to provide post-event debriefing opportunities if the session is appropriate to, and knowledgeable of, HIV related issues. Adapted clinical supervision by clinicians experienced and trained in HIV related issues was considered appropriate by some, and lacking relevancy by others. Generally, the importance of providing the opportunity to discuss events in an environment appropriate to peer workers’ experience and relevant to the work, was agreed upon by all. The specific tool utilized seemed best served by examining the needs of individual projects’ participant group, worksite location, experience of the peer worker, and any other pertinent factor that might render conventionally provided support tools inaccessible by peer workers.

Discussion of the location of the provision of this type of support was divided among focus group participants. Many favoured off-site support at an independent organization or clinic. Some preferred a specifically trained peer mentor to liaise between peer

workers and the project team. Others wished to make use of the project organization’s own counselling staff and conduct debriefing in-house. It appears that the diverse opinions directly reflected the experiences of the peer workers and researcher/service providers in the focus groups. In some cases it was because of what worked well, and in some it was because of lessons learned while undertaking the work. In all cases the emphasis was on searching for appropriate methodology and practical tools to accomplish the goal of alleviating the ‘burden of the work’ encountered by peer workers.

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*“De-briefing/clinical supervision? I think there needs to be opportunities for de-briefing with a trained counsellor/mentor who is outside of the organization where the ‘peer’ works, and also outside of any organization where the peer might still access services/health care.”*

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*“Safety in the work creates a sense of belonging. We need to foster a sense of open communication that fosters that sense of trust and safety. Establishing relationships of trust with service providers helps you to be able to navigate client/worker switching hats. I think you need to find a person who you feel comfortable sharing with.”*

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*“Having scheduled feedback and debriefing allows little things to come off the chest. Preventative debriefing helps. Don’t allow cumulative stress build up. Putting the onus on the peer for self care*



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*may leave the peer to wait too long before stress overwhelms them.”*

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### *Triggers:*

Peer workers and researcher/service providers alike recognized the need for practical help dealing with emotional and physical triggers encountered in the work. Peer workers living with addiction; experienced in catastrophic health issues; conducting work in high risk areas; formerly incarcerated; and living through other experiences requiring extraordinary coping skills when re-encountered, discussed the significance of proactively dealing with these issues. Suggestions of specific training modules on triggers, providing regular scheduled face-to-face meetings, and generally ‘someone to check in on you and see how you are doing’ tools were urged on project creators and teams who employ peer workers for their specific community experience. The very real danger of jeopardizing a peer worker’s health and/or sobriety or safety by providing access to their community needs to be carefully managed to mitigate all the inherent risks throughout the duration of the work.

### *Burnout:*

Support for peer worker burnout begins with a proactive approach. Thorough training before the work begins, active aware-

ness for the warning signs, and appropriate responses are key to avoiding many instances of burnout, and critical to successfully providing support for peer workers who experience it. Focus group participants cited instances where peer workers were reprimanded or disciplined for burnout behaviour rather than supported, and burnout was not identified as what was happening. Training around recognizing the signs of burnout was suggested for both peer workers *and* those who employ them to successfully deal with this common issue. Proximal association with the participant community, and often the worksite itself, were factors strongly associated with the high instances (anecdotal) of burnout among peer workers in many types of HIV-related work.

Many of the conventional methods of alleviating stress leading to burnout were considered effective, i.e. hobbies, nature, music, gym, etc., while others specifically adapted to HIV-related work were suggested to target common areas of peer worker burnout. These included the provision of a “peer mentor” with skills and experience relative to the project work, a “peer leader”, someone employed on the project to coordinate the fieldwork and peer worker activities, and specialized training with role plays to emphasize the worksite scenario possibilities and skills enhancement to deal with them successfully.

The perfect peer phenomenon was discussed in this context as well.



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*“Perfect peer phenomenon? When they are doing well at the beginning of the program and really successful, and will take on lots of work. However, it is on provider to recognize this and to be realistic with what individuals can accomplish and not to inadvertently encourage behaviour leading to burn-out.”*

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Both focus groups suggested being aware of the propensity to put new, very motivated peer workers on a pedestal as examples of community engagement or inadvertently portraying them as the “face” of the project. This was considered to be a primary stress factor that could potentially contribute to burnout if not closely monitored for warning signs. The lure of elevated social capital within the community was often overlooked as a sign of peer workers taking on too much and pushing beyond the scope of practice.

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*“...many peers haven't worked for a long time, the thrill of working alongside professionals is rewarding and enticing, pride is being instilled, but ends up feeding the perception of the pedestal syndrome. It's important to have a filter: how to vet projects, so not to take on too much.”*

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Successful training and ongoing monitoring of coping skills can help prevent burnout; introducing a change in routine; getting to the gym and exercise in general; seeking support outside of the HIV community, were all suggestions to mitigate stress factors that commonly lead to burnout.

## **HIV Disclosure & Managing Confidentiality:**

HIV status disclosure issues are complicated, and multi-faceted for peer workers and researcher/service providers when employing people living with HIV for their accessibility to the larger HIV community. Many peer workers do not initially make the direct connection between being hired as a “peer” and the inherent status disclosure that comes with the work. For many, training is the first instance of self realization that they are “outing” themselves to people beyond their choosing by their employment as a peer worker on a project. Most peers in the focus group reported that they came to the work prepared to protect the HIV status of project participants, but hadn't thought through their own status disclosure, and the impact it might have on them.

In all cases, the discussion in both focus groups indicated the adequate, ample coverage of discussion on protecting the status disclosure of participants through training and ongoing support activities on existing projects. It became apparent that gaps exist in adequate discussion of the legal context of the current criminalization of HIV, and how best to protect the project team, participants, and peer workers from legal action *and* the emotional impact of witnessing possibly criminal activities through data collection processes. In a sentence, the current legal context of criminalization of HIV makes disclosure awareness even more important to discuss and strategize for adequately to prevent a breach of confidentiality.



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*“I feel like a vessel of secrets when socializing in community. We need to know how to manage all the knowledge you’re privy to when doing peer work. How to edit conversations, our behaviour, social interactions, etc....I’m known as the HIV guy in the community.”*

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Other issues of disclosure that were discussed in the focus groups were regarding passive breaches of confidentiality, i.e. asking for participants at a reception desk while wearing identification, or contact in the presence of participants’ friends/family.

Coaching on how to successfully manage confidentiality while accessing personal health information as a peer worker is important to address. One participant stated “I have access to my peers health history and personal details. That can be awkward if they don’t know I know”. Clear guidelines on who has access to what information, and how best to protect confidentiality in these instances, need to be well thought and established before the work begins.

Managing the status disclosure and confidentiality of both the peer worker and the participant requires careful consideration based on the specific needs of each project, and should be assessed on a case-by-case basis.

### **3. Cognitive/Educational**

The bulk of the discussion about cognitive issues reflected suggestions on topics to be included in initial, and follow-up training sessions. Some felt that their existing training was adequate and fit the project parameters, others made suggestions of additional topics to be added in modules to augment current training sessions. The suggestion was also made to more carefully examine conventional training tools and adapt them to be more relevant to the specific work required on the project. Cognitive issues outside the scope of training included suggestions on job and/or skills enhancement, greater meaningful engagement of people living with HIV (MEPA) on project teams, and interest in the ethics clearance process. These issues are covered in more detail in other sections of this analysis. (see Service/Project Delivery and Role Models/Mentors sections)

#### *Training:*

The following is a list of participant suggested topics for inclusion in training, dependent on individual project requirements. Factors to consider when developing training modules are: population(s) to be engaged, geographic location, vulnerability of participants, gender, substance issues, urban vs. rural, social hierarchy of target population, education/skill level of peer workers, and any other factor relevant to conducting the project work.



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- We need training on how to manage self care, and balance the daily work schedule and daily tasks. Don't expect peers to know how to manage and balance new work load at first, it takes time to learn how.(boundaries and self care)
  - Training around setting personal and professional boundaries and having clarity from the very start, we need more training in this area, it can be difficult in the beginning. Non-confrontational conflict resolution and communication skills.
  - Grief and loss training is lacking in this work, need initial training as well as "reminders" during the project.
  - Successfully managing drug use and emotional triggers during fieldwork.
  - We need special population-specific training, for example Gay Peers, Women Peers, Heterosexual Peers, Drug Involved Peers to name a few. (cultural competency)
  - New peers doing this work need training on 'outing' your status, and to fully realize the implications of being 'out'. Are you going to be strong and grounded in and when unexpected situations arise? (confidentiality and disclosure)
  - Professional conduct and confidentiality are important issues to address. Guidelines are probably necessary to set rules for what levels of confidentiality need to be kept. i.e. what types

of information can be shared about clients and organizations they work for.

- Peers are at different experiential/skill levels at the start. How about if we offer training models that fit different types of peers? Some peers have higher skill levels than others and this caused a different training demand on coordinators from those peers who didn't. It is challenging for the trainer to meet everyone's needs in one group. Generic (conventional) training programs do not accommodate people with different cognitive and experiential backgrounds ... we ended up requiring a bifurcated training approach, some being conscious of others being trained differently, and the demand being placed on the trainer was on par with the training skills you would expect in college or university educators.
- Peer workers may have mental health/cognitive challenges and education (training) needs to address this.
- Understanding the responsibility of learning and retaining sensitive and confidential information gathered during the work.
- How to manage social and professional interactions. Cliques can form within peer worker circles and exclusion may need to be monitored and managed by the project team.
- Ongoing training (refreshers) beyond the initial training is essential to maintaining safety and reducing stress.



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- Annual reminders around self care and ethics, polishing up skills on handling the pressure and dealing with ethical concerns.
  - Ongoing training regarding maintaining privacy and confidentiality; the current criminalization of HIV adds a layer of complexity to the job, and safely handling self disclosure.
  - After initial training, we need orientation time, and discussion about the organizational cultural expectation that peers already know everything. The reality is it takes time for all of us to learn from each other ... it takes time to get up to speed on the nuances of the organizational culture ... it's no different from the required learning curve for a brand new (non peer) employee.
  - Consider training additional peers to be ready for back-up and to cover shifts when others couldn't make it. In our study, peers were sometimes unable to attend scheduled meetings and educational opportunities and there was no backup.

Initial and follow-up training of peer workers was considered by all to be a primary source of support, and the first opportunity to set the tone of support provision for the entire project. Training provides the opportunity for project teams to identify areas of support focus for projects, and to gauge the appropriate level of required support for the peer workers themselves during the proposed work.

#### **4. Service/Project Delivery**

Discussion in both focus groups led to issues that were considered to be the responsibility of the project team. This included addressing tokenism when people living with HIV were hired as peer workers without meaningful engagement in the project, defining the roles and responsibilities of both the project team and peer workers, administration processes and human resources issues, progressive employment opportunities and future advancement, and supervision while conducting the work.

##### *Roles and Responsibilities:*

All focus group participants agreed that defining the role of peer workers at the outset of the project was critical to its success. Researchers were reminded that Peer Research Associates are not graduate students, and as such need detailed direction on their role and scope of responsibilities within the work.

Peer workers discussed the importance of the project team acknowledging their lived experience, personal expertise and culture-specific relevance when conducting the work. With this acknowledgment also comes occasional accommodation for these exact attributes which dually make the peer worker *valuable and vulnerable* to the fieldwork undertaken.

When the roles and responsibilities are clearly defined, it reduces the chances of impact of the work going unnoticed or un-



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der reported to the project team. When negative impact issues threaten to derail a peer worker, or the project work, the framework for supporting the peer worker needs to already be in place. Initial and ongoing training identifying these issues, and the development of appropriate support tools to deal with them effectively mitigates the negative impact.

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*“There may be an expectation that the peer is an ambassador for a project in the community, but we may need to inform peers that this is not necessary. Their reputations are tied to the projects, so healthy distance is good too if projects don’t go well.”*

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There is often a subtle shift in employee-employer relationship over time. When peer workers are first hired there is keenness, and for some an overzealous attempt to become the “perfect peer”. Defining roles and responsibility limits helps with this issue.

Focus group participants described the usual employment expectations in any job to prove oneself and gain respect. It was emphasized that this takes time, and peer workers need to be gentle with themselves and supervisors need to be supportive and encouraging rather than micro-managing every detail.

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*“...there are universal situations for new peer workers, where they want to be perfect and take on too much work. However, what the exact issues are for HIV+ peer workers in this situation may need extra attention.”*

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Additionally, the expectation in community based organizational culture is that because they’re a peer, they’ll know everything about the community, or how to work with their peers. However, it takes a long time getting to know how an organization works. This is equally true for a peer transitioning from being a client of services to a peer worker within same organization.

It was emphasized that we need to be explicit about potential harms or negative side-effects of peer work when hiring peer workers for a project. By encouraging mentorship relationships and building support within and outside of the organization, we can reduce the potential for harm.

Within the scope of practice and responsibility, to enhance the meaningful engagement of people living with HIV (MEPA), we might also consider engaging peer workers in more decision making roles, for example, on a hiring committee or community advisory board, or a role in knowledge to action efforts at the conclusion of the project.

#### *Resources:*

Printed resource sheets with topic specific content for appropriate distribution, i.e. after survey completion, a handout for local harm reduction services were considered to be adequate for participants. Peer workers themselves requested more resources related to their personal and professional safety. Printed instructional sheets “in the event of...”, laminated cards



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with information deemed necessary to the work, and walkie-talkies or cell phones with immediate access to a supervisor were considered helpful additions to existing resources. Developing a repository of best/wise support practices from projects that worked well was suggested as a valuable learning *and* resource tool that did not require re-allocation of already scarce financial resources to re-create supports for each project.

Assistance and guidance for job advancement within a project, or transition to a new project was desirable to peer workers, and tools for researchers/service providers to provide guidance on how to support peer workers through their transition to other work were suggestions made by focus group participants.

The creation of a **Peer Worker Network** that could develop and provide support resources to peers and their employers was considered to be a desirable next step in the establishment of peer worker support standards. Providing resources, advice, support options of what has worked well on other projects, and general support for peer workers dealing with issues on their projects will be a valuable asset to peer workers in the future.

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*“As a first time peer researcher (consultant), who do you go to when being approached by studies to work? How do you check the integrity of the work and make sure it’s a good idea? we really need a Peer Worker consultant resource.”*

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### *Administration:*

A number of administrative type supports were suggested as helpful ways to facilitate workplace issues for both new and experienced peer workers. Providing appropriate feedback opportunities/venues, job advancement possibilities, worksite orientation, and a scheduling framework were some of the often overlooked, or not peer worker conducive workplace standards.

By having multiple evaluations (process evaluation) throughout the project, the opportunity for peer workers to talk about what works and what is not working for them provides feedback for the organizational/research team . Ongoing evaluation offers peer workers the opportunity to debrief and provide feedback on a more general level than immediate post-meeting debriefings can offer.

The organization or research team could develop unique evaluation scales that peers and supervisors both fill out. When there are discrepancies in report details, conversations can immediately happen on why that was, for example, what further support does the peer worker need or where are there gaps in expectations.

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*“What do you do with long-term peer who does not grow? Evaluations influence involvement of peer workers in projects ... past experience with evaluation provides constructive feedback and praise for what was done well, including venting re: progress over*



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*broader time frame, hopes for before project is over, hopes for after it is done, how the organization can support the worker .”*

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The traditional model of full-time/5 days/40 hours a week work is not considered a supportive work model by some, especially for folks living with HIV and additional stressors, co-infections, illnesses, etc. It was suggested that there MUST be room for flex work/job shares/part-time work, in addition to offering “full-time” positions. It is rare that a peer worker is needed to work 5 days a week, every week. Reducing the weekly hours has shown to contribute to the longevity of peer workers on projects. When flexibility is utilized, peer workers truly have opportunities for self-care/downtime outside of work.

When worksite orientation was offered by the employer at the start of engagement, many focus group participants reported feeling connected, and that this is the first step to feeling safe and supported in their work.

Knowing about an organization before becoming employed helps peer workers feel supported because they already have a history, perhaps as a volunteer, or client/member, or both. Relationships and history help build a crucial support base.

In terms of a scheduling framework, having a designated plan if a peer worker cannot make a shift, or plans to accommodate sick days, or short notice absences is critical to keeping the pro-

ject on track. One creative solution is to have multiple people trained for a single peer worker role, and have a pre-determined system in which people fill in (on call) shifts as required.

#### *Employment Opportunities/Advancement:*

Providing for peer workers beyond their initial project engagement, and offering advancement opportunities within, and post-project was echoed by peer workers and employers alike.

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*“In the context of funded research projects, we should help people develop skills to move beyond that framework ... a strategy should be in place to transition peer workers into another appointment, or other research work.”*

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It was suggested that using project down time, or lag time waiting for ethics approval, for example, could provide opportunities for offering professional development and extended training.

Another important concept to come forward in the focus group discussion, was to create a safe procedure for an exit strategy; a process for a person to shift from one project or job type to another, and feel supported in that process.



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### *Supervision:*

A non-traditional approach to supervision was considered essential by the peer worker group. Several issues were discussed, encompassing accountability, worker safety (both physical and emotional) in terms of maintaining rigorous data collection in challenging outreach locations, and regular performance issues. Some of the discussion is best presented in the words of the participants as follows.

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*“Trying to “control” a team is not the best solution...building a team from a solid foundation of trust, support and open communication with encouragement, specific and appropriate training will empower all members of the team to get it going in the right direction, and redirect back when off course.”*

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### In contrast to that comment:

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*“In the context of IDU peer outreach, there is often a question of whether the work is getting done. Suspicion that workers go home when on outreach is somewhat common. From a coordinator’s perspective, how do we ensure accountability for the work getting done? One way to handle this issue is to create a log book of activities with a contact person at outreach sites that the coordinator can check in with if need be.”*

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It was further suggested that a lack of understanding on the part of employers/supervisors regarding addiction, race, gender, culture, etc., adds to unrealistic expectations of peer worker individuals, and comprehensive awareness/sensitivity training on these issues was suggested for all would-be employers of peer workers.

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*“What about workers whose performance perhaps needs to be monitored, e.g., workers with clients in the context of drug addiction outreach ... what subtle checks can be in place to assure that there is no perception of mistrust, yet still obtaining confirmation of the work being done? ...one way is to have a ‘facade’ that checking in on a person could happen, but not necessarily doing it very often, or as is required.”*

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For day-to-day operations, the following suggestion met with majority approval:

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*“A competencies checklist allows the peer worker to self evaluate and compare the supervisor's/coordinator's evaluation of the same factors ... disparities can then be examined and addressed. This has worked well in the context of our organization with six month followup checks for positive change/progress. When observing unsafe and situations that are not working, how far do you follow (supervise) a person? ”*

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The pros and cons of an “open door” policy in the context of supervision were hotly debated, with many in favour of full access



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and working together to problem solve issues that arise. Others had concerns regarding determining the appropriate lengths to go to for individual peer workers in relation to the rest of the team.

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*“ When a peer isn’t working out in the job, how far does support go? This can lead to further tension, and enormous stress for the rest of the team.”*

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*“ Open door policy with my supervisor is very helpful by creating a safe space in which to relate ‘what is going on with me’ one on one, as a human being. I feel completely supported.”*

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*“ Open door policy is good, but perhaps a combination of both – regular debriefings and scheduled debriefings accommodates those who may not realize – or are in it – that they need to debrief, not bottle it up.”*

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The researcher/organization focus group also discussed the reality that “...in research world, projects have short lives and funding gaps. When a projects end, peer workers can fall hard when the job is over. Projects should build into budgets ways to train peer workers to transition to new work.”

All participants agreed that feeling like a valued part of the team is very important. It was agreed that supervisors/coordinators

need to follow through with support, and encouragement, they need to “walk the walk not just talk the talk.”

## 5. Role Models/Mentors

One of the most interesting points of discussion came up around the utility of role models, or mentors, for peer workers to draw on for support. It was considered to be the preferred method of appropriate support in most of the focus group analysis categories previously outlined in this report. It was also mentioned as a desirable next step for peer workers to aspire to after their initial work experience as a peer worker. Helping others in similar work settings, and utilizing the experience gained as a peer worker, as well as practical, accessible job advancement, enables peer workers to continue on an employment trajectory that often starts as a peer worker on a project. A lack of existing role models and/or mentors trained to support peer workers, spawned the idea of creating a peer mentor training program in the future, where peer workers with a desire to become “more” could be trained in specific support skills as a mentor. Other venues where this concept was suggested received widespread enthusiasm for the creation of a mentor training program as an extension of support provision in the future.



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The focus group participants had practical suggestions on why this concept is important, and how it would benefit project teams and peer workers alike.

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*“ One-on-one peer mentors could play a role to help prevent ‘venting’ with other peer workers on a project.”*

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*“ The role of peer mentor could be to focus the project group on capacity building, rather than venting”*

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*“ When, and if peers advance on to a mentor role. We need specialized training for peer worker mentors.”*

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*“ A Peer Worker Support Network would be great to implement and have access to on an ongoing basis.”*

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*“ We need a mentor who can help you check yourself!”*

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*“ Peers come from all walks of life and may already be in professional work environments. How do we offer professional peers support on a ‘higher level’?”*

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*“ Where do high functioning folks go for peers? There needs to be a diversity of experience in the context of needing a peer support person ... we also need to be including professionals.”*

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A couple of cautionary comments worth noting:

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*“ If there’s a perception of there being a cool peer mentor group, the jobs become coveted, and that might create (undesirable) pressure to become a part of that group.”*

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*“ When a peer is perceived as the likely ambassador for a project within the community, if something goes wrong with that project you are inadvertently associated with that failure. (considered a negative association)”*

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Overall, the consensus was to encourage mentorship relationships, and build within and outside of the project/ organization whenever possible. The general message was to ensure the provision of support by someone who fully understands the specific issues relating to peer workers, has the appropriate skills to provide the support required, and that the mentor position become a budgeted, integrated piece of the entire project framework.

## **6. Financial Compensation**

The Pacific AIDS Network (PAN), recently struck a small working group specifically to examine this issue. The following “CBR Tips” is the resultant info sheet on the topic of compensating



peer researchers. This could very well be adopted for any other forms of peer worker employment beyond research projects.

## CBRTips

### Compensating Peer Researchers

#### Background

In community-based research, compensating people with lived experience to participate actively in the research process is a common practice. Peer research associates (PRAs), as these individuals are often titled, can take on diverse roles within community-based studies, and compensating PRAs for their input of time, skills, and expertise is considered a best practice. Making payments to people with lived experience is intended to support inclusion and the effective and equitable participation in research processes by easing financial constraints. Further, having clear policies and procedures around compensation can be helpful in clarifying expectations and responsibilities relating to people's involvement.

Developing a compensation plan with PRAs can be a complex task and many factors should be considered, such as the financial administration rules of your institution (e.g., university or non-profit organization) and of the funder. It is also crucial to consider the potential impact that receiving financial compensation may have on a PRA, including their eligibility for other forms of social assistance, such as disability benefits.

This document was developed in consultation with PRAs, research coordinators, administrative staff/financial managers at community-based organizations, and academics within British Columbia. It outlines some important considerations to take into account when developing compensation plans and policies for community-based research. Rather than being prescriptive, these tips are meant to encourage discussion on best practices and foster the formulation of guidelines tailored specifically for each context. Because each situation is different, this document is not prescriptive around rates of payment or procedures, as these will always depend on a number of variables. The key message is that every research project is unique, as are the financial realities of PRAs, and each study or project team will need to develop their own approach to compensation in consultation with the PRAs who are involved.

#### General Considerations

- There is no "one-size-fits-all" model. Determining how to compensate PRAs is a fluid process, which requires much thought, discussion, flexibility and time. Individual PRAs may have different concerns, and you may end up with different compensation arrangements for different people.
- People choose to participate in research teams for many different reasons – to make a contribution, to gain new skills or access to hands-on training, to connect to new people, to build community. While offering payment in the form of monetary compensation is important, other forms of acknowledgement should also be included in projects. This can include thanking and acknowledging individuals for their contributions, offering other forms of rewards, such as access to training, participation in conferences, and support in developing CVs or access to future employment.
- Receiving monetary compensation for participation in the research process may have an impact on the financial benefits that a PRA receives from other sources. These sources may include payments from provincial disability or social assistance programs, private insurance, Canada Pension Plan and housing subsidies, to name a few. Additionally, PRAs who are Aboriginal and live on reserve, or are status and are working for an organization based on band land, may also have distinct needs relating to taxation that should be considered.



[www.pacificaidnetwork.org/resources/cbr](http://www.pacificaidnetwork.org/resources/cbr)

1 Last updated: June 10, 2014

## 7. Next Steps and Possible Applications:

As several of the suggestions made by peer workers and researcher/organizations during the focus group gathering phase are immediately actionable, plans have already begun to operationalize the ones considered urgent, or realistically achievable with minimal additional financial resources. For example, walkie-talkies and cell phones to enhance communication with the project team and physical safety at outreach locations, is now common practice.

A funding application was developed and submitted to the Canadian Institutes of Health Research, CBR Stream this year, to begin designing and development of a pilot training program for Peer Research Mentors as suggested by focus group participants. The grant application was successful, and work is well underway designing a peer researcher self-assessment readiness tool for anyone interested in applying for the pilot training program to become a mentor. The training modules will feature enhanced communication and support skills suitable for mentorship, and is a fully collaborative project including researchers, organizations, and peer researchers themselves in its design and delivery during this pilot phase.

Many other suggestions for enhancing support in existing projects have been adopted by researchers and organizations whom currently employ peer researchers, and new project de-



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velopment is now including many additional support-related provisions in their applications as budget line items.

The goal of this entire discussion process on providing adequate, appropriate support for peer workers, is to offer an organic industry standard for support provision. It is hoped that by offering the features and benefits of peer worker support tools as suggestions for inclusion in newly developing projects, that this will generate awareness of the often unique needs and challenges facing peer workers living with HIV/AIDS.