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Health Education Journal published online 5 September 2014
DOI: 10.1177/0017896914547660

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What is This?
Establishing an online HIV peer helping programme: A review of process challenges and lessons learned

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Abstract

Background: Online peer support can be a valuable approach to helping people living with HIV, especially in regions with highly rural populations and relatively centralised HIV services.

Design: This paper focuses on a community-university partnership aimed at developing an online peer support programme in the Canadian province of Newfoundland and Labrador.

Setting: Team members included community representatives and people living with HIV from the AIDS Committee of Newfoundland and Labrador (ACNL) as well as academic researchers.

Objectives: Goals and objectives of the programme included reaching disconnected people living with HIV, reducing isolation among people living with HIV and connecting people living with HIV with support, education and professional resources.

Method and Results: Through a process orientated and iterative decision-making approach, the team established the website, peer helping training curriculum, a recruitment plan as well as other core considerations. The current paper emphasises several process challenges and lessons learned from the development stage of the online support programme.

Conclusion: It is hoped that this information will assist others in avoiding or overcoming similar process challenges arising during such work.

Keywords

HIV, online peer help, online peer support, process, development

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Rationale and context

There is no online support network for persons living with HIV in Newfoundland and Labrador (NL), despite significant geographical barriers for many people living with HIV to access support. NL’s population is relatively small, rural and geographically spread out. This rural population is contrasted with a relatively large subsection of the population that lives and works in an urban centre. Many people living with HIV in NL live outside of this urban centre and thus have less access to dedicated HIV services and support (NL HIV Programme, May 2014, personal communication). Many people from NL also migrate to western Canadian provinces for work. These provinces are thousands of miles away from NL, and thus, their families and sources of support are often unavailable. Internet-based services have the potential to bridge this gap in support services. An online support platform was developed during 2012–2014 to reduce barriers in accessing face-to-face support services such as fears of stigmatisation, concerns with lack of anonymity and social anxiety. This paper describes some of the key process challenges and lessons learned in developing and establishing an interactive website that provides HIV knowledge and peer helper support in NL.

Online social support

Reported applications and benefits

The importance of social support in coping with HIV has been widely documented and has been associated with various positive outcomes (Mo and Coulson, 2007). Specifically, social support is associated with higher immune function, greater use of active coping strategies, improved quality of life, adherence to medication and better psychological health among people living with HIV (Mo and Coulson, 2007). Unfortunately, numerous barriers often prevent people living with HIV from using face-to-face support services. Online support groups can satisfy the social needs of people living with HIV by connecting them with peers who are faced by the same needs (Coursaris and Liu, 2009). In her 2000 review of online support groups for individuals with HIV, Finfgeld concluded that online interactions appear to mirror face-to-face exchanges and participants report higher quality of life scores and fewer negative emotions than controls. She also described increased confidence in decision-making and a reduction of social isolation and strain (Finfgeld, 2000). Mo and Coulson (2007) had similar findings. Among the more than 5,000 messages on an online support group bulletin board that were reviewed, the authors discovered five types of social support – primarily informational and emotional support, followed by esteem support and network support, with tangible assistance the least frequently offered (Mo and Coulson, 2007). Other studies have reported comparable findings, deducing that online support groups and health-related Internet use are associated with higher levels of social support (Mo and Coulson, 2009).

Overcoming traditional support obstacles

Rural–urban disparities in population health and access to care have been well documented (Veinot and Harris, 2011). Access issues are particularly significant for people living with HIV who reside in rural areas. Online support groups enable diverse populations to communicate with each other regardless of physical geography (Bowen et al., 2008). In their 2011 study, Veinot and Harris found that rural-dwelling Canadians, including Newfoundlanders and Labradorians, were less likely than their urban counterparts to be knowledgeable about HIV or to talk about it. Online support/education programmes can help to bridge this gap in knowledge and communication. Other barriers to accessing services and support for people living with HIV include stigmatisation towards the
disease, physical limitations, privacy and confidentiality concerns and social rejection (Coursaris and Liu, 2009; Mo and Coulson, 2007, 2010). For those who experience interpersonal discomfort in face-to-face settings, access to information and support online can be particularly beneficial (Finfgeld, 2000). Furthermore, online support groups offer relative anonymity that is not possible face-to-face, thus reducing the possibility of being identified and potentially facing discrimination. This can be especially helpful for men who tend to be more hesitant about participating in therapeutic groups. Mo and Coulson (2007) reviewed data that were obtained from messages posted to an online HIV support group bulletin board. The researchers found that the online support group provided a useful context through which members could discuss the anger, fear and frustration resulting from HIV-related stigmatisation, feelings of isolation as well as the recurrence of symptoms resulting from medication. Online delivery affords individuals privacy, immediacy, convenience, anonymity, a large variety of information and a variety of perspectives on the same topic (Bar-Lev, 2008; Cotten and Gupta, 2004).

**Online programme delivery**

Online support groups can operate through various Internet applications – email lists, chat rooms and forum or ‘bulletin boards’ (Barak et al., 2008). According to Barak et al. (2008), participants are more likely to choose forums. Participants are thought to appreciate the synchrony of the experience and enjoy features like easy access, archival searches, access to emoticons and links and welcoming website designs (Barak et al., 2008). In recent years, a newer online medium has become available – social networking sites. With their growing popularity, multi-functionality and a decreasing digital divide, social networking sites, such as Facebook, Twitter and MySpace, offer the possibility to scale HIV prevention and interventions among people living with HIV and high-risk groups like never before (Jaganath et al., 2012). At this point, studies incorporating social networking sites and peer-led interventions for people living with HIV are limited, but the possibilities are extensive (Jaganath et al., 2012).

**Methodology: community-based paradigm**

The current project followed a community-based paradigm (Harris, 2006). Such an approach is process focused and connects researchers and community members to facilitate collaboration in order to address a community question or need (Radda et al., 2003). In this type of work, community members are active and equal partners in all stages of the project and have significant and meaningful input into project related decisions. Collaborative and egalitarian relationships are at the core of community-based approaches (Harris, 2006). Process is a key aspect of such work, including being open to learning from the process as seen through various stakeholder perspectives.

**Partners**

The project was conceptualised through a partnership between the AIDS Committee of Newfoundland and Labrador (ACNL) and Memorial University. Project members included people from various disciplinary and lived experience backgrounds and represented staff, people living with HIV and researchers. Our team functioned largely through in-person or email group discussion. Thus, all members contributed to the direction, timeline and outcomes of the project. Our team included the provincial HIV service coordinator who acted as a project coordinator and leader for many of the training sessions. The Executive Director of ACNL was also involved in the project.
as a coordinator. Our peer helpers were involved in all team discussions and decisions, contributing to project leadership. They were also involved in the development of the peer helper training curriculum. The team included an information technology (IT) specialist who led much of the technology end of the project. Several researchers and graduate students were also involved in the project, and contributed as well to leadership, literature reviews, writing, evaluation and training aspects of the work. We were fortunate to be able to include several additional professionals from the HIV treatment team, including the local health authority, to be involved in various aspects of the peer helper training.

**Online peer helping in NL**

This paper presents a series of challenges and lessons learned in creating an online peer helping programme in NL. We started this work with an idea and an existing website that was largely content based. We developed a funding proposal and engaged in a literature review (i.e. grey and academic) of peer helper programmes, including delivery models, training and curriculum considerations and evaluation methods. We spent significant time establishing our team, setting objectives/goals and developing a working plan (see lesson 1 below for further description of this work). We established a training curriculum and engaged the peers in this training. Throughout the development process, we conceptualised the website including the content to be displayed as well as the support mechanisms that would be included. This online programme involves a number of core components including educational resources (e.g. links to specific articles on topics important to people living with HIV), a listing of referral agents (e.g. professionals whom could be sources of support to people living with HIV), a message board (e.g. a community board where anyone can post questions or responses that others can view), chat room (e.g. a separate space where a small group of people can post messages back and forth to each other while being moderated by a peer helper) and one-on-one chat functions (e.g. where a service user can have a private live chat with a peer helper during specified times). The peer helpers, who are people living with HIV with specific training in peer helping, are largely responsible for the day-to-day monitoring of the website, with consultation and supervision provided by the provincial HIV coordinator at the ACNL.

**Process challenges and lessons learned**

The following represent 10 significant lessons learned during the development stages of establishing an online peer helper programme for NL. These stem from process challenges and successes experienced by the team. These 10 lessons were chosen by the team as we believe they were the most significant considerations we addressed as we developed this online programme. We also believe that these lessons would be the most relevant to others contemplating such an online programme. They are presented below in no particular order of significance, although we have tried to present them wherever possible as a timeline from early in the project development phase to late in the project development phase. In practice though, many of these challenges needed to be returned to throughout the process.

*Communication lies at the core of effective partnership and programme development*

When the project initially started, we did not have a communication structure or plan in place, and this had impacts on how well we were able to communicate and work. Part of the effectiveness and
value of this project quickly became rooted in the team approach taken to the work. Once we established an effective communication plan, the work became increasingly efficient and effective. The team made use of regular meetings facilitated by the local community-based HIV organisation (ACNL). This proved to be a useful and neutral space for the various project partners to meet including people living with HIV, members of the ACNL and academic researchers. Through multiple team meetings consisting of a process orientated and iterative decision-making approach, the team established specific characteristics of the website, a tool to assess the website, training curriculum as well as a plan to recruit people living with HIV to the website. The team was very respectful in its communication processes, and members of the team were very comfortable and open in sharing their views, concerns and ideas. People listened and responded in thoughtful and considerate ways. Discussions tended to continue until consensus was reached, and sometimes this required ending meetings to ‘think on’ certain topics, draw in outside resources/perspectives and make time for reflection. Following such reflection, impasses tended to be bridged. As examples, the team had different views on the use of discussion boards for the site and who would have the ‘authority’ to remove problematic posts. Another example was around site users expressing suicidal thoughts and the different views that team members had on what appropriate responses would include from the peer helpers in such situations. Again, through respectful discussion, active listening and being open to multiple views, the team was able to work through such complex challenges. Appreciating that this community-based work was highly process focused and that team members had different experiences, worldviews and perspectives allowed members to focus on learning, relationship establishment and consensus building.

*Having project coordination, people involved in the work present at the project site and building in extra time*

One of the challenges starting off with this work was establishing a project coordinator. Early in the work, ACNL had vacancies in some core positions, and this resulted in the absence of a dedicated community-based project coordinator for the project. In many ways, this shut down the project. Once ACNL vacancies were filled and a project coordinator was identified, the project quickly regained momentum. Having an onsite community coordinator allowed important work to be accomplished and facilitated the project ultimately maintaining a key community-based focus. As the project continued to unfold, we were fortunate to be in a position to hire a technology expert. This allowed us to have full and continuous (onsite) access to someone invested in the project and highly knowledgeable about online technology. This proved time and time again to be critical to the project’s success and was not part of the original budget or plan. Related to the above points, establishing communication and coordination structures in such projects takes time. Unexpected events happen, and thus, ensuring extra and flexible timelines is important.

*Peer helper recruitment and retention needs to be an ongoing consideration*

Identifying potential peer helpers was an important consideration early in the project. We had originally identified three peer helpers, but one opted to not stay involved. This left us with two peers living close to ACNL (i.e. within driving distance). Proximity was important at this stage due to their active involvement as team members as well as their involvement in the training. Peer helpers were recruited through existing ACNL networks. In considering potential peers, interest, motivation and maturity were key peer characteristics. Technological literacy was also an important consideration because the technology learning curve can be a deterrent. During the development stages
of the project, having peers who were knowledgeable about the issues, were experienced and were willing to take a leap of faith regarding some of the challenges and issues was critical. We could not afford to lose our peer helpers as they became such a critical part of the team and significant resources had been invested in them in terms of involvement and training. Retention considerations included intrinsic motivations such as ongoing support, training opportunities, having a voice in all aspects of the project and presenting the project as an opportunity to help other people living with HIV. Extrinsic motivations such as a laptop and a small honorarium were also key considerations. Peers informally made comments throughout the process that suggested they appreciated these intrinsic and extrinsic considerations. Going forward, all people living with HIV accessing the peer helper support website will be seen as potential future peer helpers. Given the importance of invested peer helpers in the success of such work, recruitment needs to be continually ongoing and retention needs to be an explicit and continuous consideration.

**Peer helpers need significant input to meet their training needs, and training should be a blended model consisting of upfront and ongoing opportunities**

Peer helpers come from a variety of backgrounds and experiences and thus training is a key way to help ensure everyone has certain skills and knowledge preparation. Identifying the needs of the peer helpers was critical as the number of training areas can be daunting and overwhelming. It became clear early on that training needs must be identified through a group process, including significant input from the peers themselves. This occurred largely through a discussion framework where peers were asked about their needs in an open ended manner. This process involved brainstorming to establish curriculum topics, curriculum objectives/goals, and instructional delivery methods. In preparation for these meetings the literature, available training models, and other peer programmes were reviewed and consulted to establish best practices. Thus, following open ended discussion, additional training topics were presented and feedback was received from peers and the broader team. A valuable additional feature of this process would have been a pre-learning assessment to measure existing technology skills and knowledge, and this would have allowed for even more tailored training to occur around the peer’s technology needs from a scaffolding framework.

An upfront and ongoing training model was established. Upfront training included those areas identified by the team as core (e.g. computer skills and security, self-care, roles and responsibilities, HIV testing, counselling and engagement skills, HIV 101). Community stakeholders played significant roles in offering this training (e.g. pharmacist, social worker, psychologist) which facilitated further partnership building, increased awareness of the service, provided peers further opportunities to identify potential referral agents and proved to be cost effective. Given that so much training is needed, the team agreed that an ongoing training model would be critical and that topics emerging in supervision would be flagged for further training opportunities (e.g. suicide prevention).

**Navigating dual roles and being comfortable with addressing ‘grey’ situations**

Part of the complexity of this project lay in the existence of dual roles. Peers took on ‘formalised’ peer helping roles while being informal supports to friends, being themselves potential service users at the organisation as well as being board members with the organisation. Peers needed to be aware of the implications of ‘wearing different hats’ and how to manage their various roles. We were fortunate in having recruited two peers with extensive maturity and experience, but we
realised that part of the training would need to consider dual roles. This complexity created a need
to differentiate between the various roles of peers to ensure everyone understood boundaries and
potential boundary incursions. Again, ongoing communication and dialogue helped to work
through some of the challenges associated with these types of situations.

Many of the functions of the technology aspects of this project were straightforward. Often
times, things were seen in dichotomous ways, for example, the technology will allow you to do that
or it will not allow you to do that. However, the human factors components of this project were
seldom presented in these terms. As a team, we encountered a number of ‘grey’ areas that required
considerable discussion and consensus building to reach workable and acceptable outcomes.
Examples included negotiating dual roles as described above, determining appropriate levels of
‘intervention’ on the part of the peer helpers (this is further described below) and reaching consen-
sus around how computers would be securely used outside of ACNL.

Organisational liability and peer helper self-determination

Throughout the development process, we encountered instances where we had to balance organi-
sational policies/perspectives with the perspectives from our frontline peer helpers. We had situa-
tions where peer helpers would discuss how they would handle certain scenarios with service users
and, at times, this would be a contrary approach to organisational policy. As an example, this came
up in the context of service user suicide risk, when peer helpers commented they would provide
personal phone numbers and contact information to ensure the service user was safe. On the one
hand, this has implications for issues such as self-care, anonymity and confidentiality, but on the
other hand, this was seen from a lived experience perspective as being critical to appropriate care.
When such differing views emerged, we engaged in balanced group discussion and problem solv-
ing to generate and evaluate various options and potential pros/cons associated with different
routes of action. It was critically important to not let one way of ‘knowing’ trump another way of
‘knowing’. Different opinions needed to be expressed and a safe space needed to be created in
order to have a productive conversation on the options available.

Knowing the infrastructure plan to ensure existing site is appropriate to avoid
extra work

In order to incorporate the functions needed to host an anonymous online peer support project,
ACNL needed a complete website redesign and a large amount of resources compared to the exist-
ing website. We switched over from a basic website design to a design that used the Drupal Content
Management System (CMS). We then had to install 216 separate Drupal modules in order to main-
tain our current website content while enabling the features for the peer support project. The mes-
sage board and chat functionality came at the cost of slower response time on our website and
required switching hosting providers in order to secure the random access memory (RAM) and
bandwidth needed to run all the modules concurrently. This required a minimum hypertext pre-
processor (PHP) memory allocation of 256 MB on our hosting server, and we had to migrate to a
new hosting provider which could provide the resources needed. The transfer to the new host was
a relatively large undertaking that delayed our progress significantly.

In order to prepare for a project of this scope, preliminary research on various hosting provid-
ers needs to be completed. First off, knowing whether a shared hosting plan is sufficient or a dedi-
cated hosting server would be needed is important. In our case, a shared hosting provider was
unable to allocate the resources we needed as our hosting server was being shared with a large
number of other websites and the resources we required were not available. Second, the cost of such a service should be known. Shared hosting plans are generally less expensive, but this comes at the cost of a lack of resources and an inability for the hosting server to handle the overhead of the site. Third, it is important to know whether the hosting provider allows a service such as this to run on their hosting server. Each host has their own preferences on what types of services and content they allow clients to create/provide, and this information is generally written into their service agreement.

The ability to post content anonymously

Early on in the process, we discussed the possibility of having a website that required someone to be invited before they could join the discussion. We quickly realised that this would prevent us from reaching many people living with HIV. Part of the compromise to this was a recognition that we needed to have a website that would allow people to log on and comment anonymously. This feature was important due to the stigma often associated with HIV and the difficulties in keeping HIV status information private in smaller, rural communities. We had a number of discussions about the pros and cons of anonymous posting and decided that the site would need to be monitored to remove any hurtful postings or messages. In the development of the website, we facilitated anonymity through multiple procedures. First, all users can create an account that is not associated with a personal email address or their name. Due to software limitations, an email is still required for signup, this is to prevent bots from signing up multiple accounts and flooding the message board; however, once verified, any reference to the email account used is removed. Second, the purging of Internet protocol (IP) records after signup is also performed. This ensures that should our database become compromised, there would be no personally identifying information that would be leaked. Third, the chat function uses either Secure Sockets Layer (SSL) or Transport Layer Security (TLS) encryption to ensure that data passed between the peers and the service user are secure and confidential. Finally, service users are unable to set up private chats between each other; they can only open a chat with a peer helper.

People have various needs and thus online support has to offer various options

Part of the challenge with this project was finding a balance between offering everything to support users versus offering enough to support users, while considering the overall budget and resources available. We opted to develop options through group discussion, considering available needs assessment data and literature. We were also fortunate to have team members who had a very good sense of the needs of people living with HIV in the province. We developed support options that were both real time and time delayed support. The one-on-one chat, chat room, message board and knowledge base are all used together in order to facilitate communication. Under this model, there is always a communication platform available regardless of time zone differences, sleep schedules, holidays and the like.

The chat room is used primarily as a place for an open ended discussion among multiple service users and peers. It is directed by the choice of topic, as well as the peer helper’s moderation. This helps to ensure that any hurtful messages in the chat room can be addressed quickly. The chat room is closed when no helpers are available to moderate. The one-on-one chat is a completely individual experience. The peer helper attempts to direct the discussion towards being productive; however, the tone, pace and topic of the chat are ultimately decided by the service user. Unfortunately, the anonymity provided makes intervention in the event of an emergency difficult if not outright impossible. The one-on-one chat is unavailable when there...
are no peer helpers available. Determining a specific weekly schedule for availability was also a key early priority. The message board is used for topics of interest as well as time delayed support. This allows service users to assist each other (within reason), as well as getting support from the peer helpers. A large portion of the peer helpers’ and IT staff’s work involves moderating the board to ensure no harmful messages appear (e.g. spam, personal attacks). The current website contains up to date information on various sexually transmitted and blood-borne infections as well as testing site information, support services and resources specifically tailored to various at risk groups. All these resources are meant to be used as a knowledge base for both service users and peer helpers in order to increase confidence and to reduce inconsistency in the information provided.

The importance of ongoing formative evaluation and planning early in the process for how the service will be sustained

Formative evaluation has been ongoing through internal team discussions and regular process reports to the funder. It is important to have ongoing critical discussion and for people to feel safe and valued so that they are comfortable asking questions and being critical. We did not build in a formal evaluation framework during the process/development stage other than our regular funding reports. In hindsight, a formal approach may have been beneficial and could have included an anonymous survey or potentially even an interview process with an external interviewer. The team developed a survey measuring variables such as satisfaction and site usability for people accessing the site. Another important consideration was that of sustainability. The funding we received was for 1 year to develop and launch the site. It became clear to us early on that we needed to find a way to build in support for the site in the regular operating budget for ACNL. This would allow for this critical source of support to continue following the formal end of funding.

Discussion

Online peer driven support has the potential to reach marginalised people, break down isolation and stigmatisation and become a critical support for people living with HIV (Messias-Hilfinger et al., 2009; Mo and Coulson, 2007). We found very little research exploring online interactive websites for people living with HIV. Based on our reviews of existing websites, typical websites tend to provide resource links, education and information as opposed to interactive features. Where such interactive features exist, they more commonly seem to include ‘ask the expert’ options through public discussion boards. The current project offers a broad range of interactive features that allow service users public versus private options as well as live options, when available. As well, although ‘experts’ are consultable, our site is mainly peer driven. Some existing websites offered more general health based information, so although people living with HIV could post a question about HIV, such sites tended to include information and services for people dealing with a range of health issues. We did not find any websites exclusive for people living with HIV that included a range of interactive functions and were driven by trained peer helpers who were living with HIV. This certainly does not mean that such sites do not exist, only that we were unaware of such sites. Taken together, the current project offers a relatively unique and promising approach to supporting people living with HIV.

Although developing an online peer support programme presents challenges, having a strong community-based team can facilitate solutions to emerging obstacles. At the heart of community-based work lie relationships (Harris, 2006). Relationships were a foundational component of the current work and underlined much of the team building, process discussions and outcomes associated
with this project. Being open, flexible and willing to discuss difficult considerations allowed the various team members to connect through an iterative process in order to reach the team’s goals (Harris, 2006; Radda et al., 2003).

As discussed above, we learned a number of lessons in overcoming emerging challenges through this work. Peer recruitment was a key consideration early on in the work, and identifying peer helpers with experience, motivation, maturity and close geographical proximity to the ACNL all proved to be important. Peer leader recruitment commonly occurs through online flyers, advertisements in community outreach organisations and by recommendation from professionals familiar with the target populations (Broadhead et al., 2006; Dickson-Gomez et al., 2011). Potential to be peer leaders because of their network connections or obvious influence on their peer group was also an aspect identified in the literature (Jaganath et al., 2012). Many studies reported allowing individuals in the target population to become peer helpers provided they were willing and interested to join (Jaganath et al., 2012; Maticka-Tyndale and Barnett, 2010). The Centers for Disease Control and Prevention (CDC, 2007) proposes that peer volunteers should be non-judgmental, should not have their own agendas that conflict with the programme objectives, should live or spend time in the target community and should be able to be located for follow-up.

Helping to ensure peers wanted to stay involved in the project was also a key consideration. We utilised a range of intrinsic and extrinsic retention strategies in this work (e.g. training opportunities, laptops). Monetary as well as non-monetary incentives were reported in the literature as useful for retaining volunteers (Jianghong et al., 2012; Maticka-Tyndale and Barnett, 2010).

Our team spent significant time on the topic of training. As discussed above, key decisions included the goals, content and delivery methods of the training. The timing of the training was also considered. We identified a range of training topics (e.g. communication skills, HIV 101) through open discussion and review of various information sources. The amount of training to be covered can be daunting, so an upfront and ongoing training model can be a valuable consideration. Some common goals for training people living with HIV as seen in the literature include having peer leaders feel comfortable talking about sensitive topics with their network and reinforcing the importance of their work (Amirkhanian et al., 2005; Jaganath et al., 2012; Maticka-Tyndale and Barnett, 2010). Introduction to the programme, including goals, target audience for the programme, community or areas targeted for the intervention; basic HIV knowledge; roles and responsibilities of peer educators/supports; social/cultural context; communication; ethics; effective communication skills; learning how to deliver HIV-related messages in naturally occurring conversations; and tailoring messages to unique circumstances of different peers, were commonly discussed objectives of the training (Amirkhanian et al., 2005; Jaganath et al., 2012). Literacy (both verbal and textual) and self-care are also integral training considerations (Maticka-Tyndale and Barnett, 2010). Consistent with the current work, training also tended to occur in smaller groups (Amirkhanian et al., 2005).

Conclusion

The development of an online peer support programme is complex and resource intensive. Having a multidisciplinary team, strong community input and support, onsite technology expertise and people living with HIV leadership can result in a productive process and an online support programme for people living with HIV. Maintaining openness to the process, along with building and maintaining strong relationships, can result in the opportunity for ongoing dialogue and formative evaluation, which can result in learning about what works and what does not work. As seen in the current paper, establishing an online peer platform requires considerable reflection and attention to core details.
Funding

Project funding was provided by the Positive Action Canada HIV/AIDS Innovation Program 2012, an initiative of ViiV Healthcare.

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