



Users' Perspectives on the Services and Programs that a non-profit HIV/AIDS and Hepatitis C organization should Offer

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Background

AIDS Community Care Montreal-(ACCM) is a volunteer-driven community organization that provides support services for people living with HIV/AIDS and/or hepatitis-C. Our programs aim to improve the quality of life of our members and encourage their personal development.

While Covid-19 pandemic has restricted us to schedule in-person gatherings, we have been offering some programs online that we offer include

Our organization offers programs under 3 divisions

1. Support services which include 1-on-1 Support, Buddy Program, Buyers Club, Dinner & Discussion, Discussion Groups
2. Education for Prevention activities which include sexual health workshops, sexual health kiosks for schools and special events, SextEd (a texting helpline for youth seeking information about sex and dating), Kontak (a delivery service that provides with safer sex materials and wholesale priced sex toys), and Jeunes Queer Youth (funding program and support for queer and trans youth leaders for them to create their own sex ed initiatives).
3. Treatment Information programs which include treatment support, workshop series around My Life with HIV, treatment information, HIV & aging, and navigating the healthcare system in Quebec.

Pathway

Opinions of service users have been recommended to prioritize when designing services in non-profit organizations. While we provide various services, the motivation for this project was to create an opportunity for our members to voice their perspectives on the current program and services spectrum of ACCM.

Therefore, the **objective** was to describe the members' perspectives on the services/programs that ACCM should provide in 2021.

While there are several instruments that captures the service user's needs, we used the Patient Generated Index (PGI). It was originally developed as a measure of health-related quality-of-life, but we modified the name as Person-Generated Index for this project. The PGI allows people to identify and rate services/programs that are important to them.

Telephone interviews were conducted with the members and participants were asked to nominate up to 5 services/programs that should be prioritized by ACCM. Then, they were asked to rate each service/program on a scale of 0–5 (not at all important to extremely important)

Findings

Communication information existed for 75 of the 200 ACCM members. Of those, 20 were contacted and 5 members responded. Four of the 20 contacts were out of service. Therefore, we reached a response rate of 31% which is considerably low.

Mean age of the 5 participants were 56.4 (range: 59-66), 3 identified as male, 1 as female and 1 did not respond. Average time of living with HIV was 24.6 years (range: 12-34) and average time with ACCM was 12.8 years (range: 8-25). Of the 5, 3 were active service users of ACCM and 2 were inactive.

The most nominated services and programs were as follows according to the ratings:

- Buyers club (4 times and rated as extremely important),
- Dinner and discussion (3 times and rated as extremely important),
- Discussion groups such as women's group and treatment info (3 times and rated as extremely important),
- Group activities such as day camp, cooking classes, arts & crafts or documentary night (5 times and rated as moderately to very important)

Lessons Learned from this Research

4 services/programs were predominantly named by our members were buyers club, dinner and discussion, general discussion groups and group activities.

Buyers club is run entirely by volunteers in collaboration with various local businesses that donate prepared dishes as well as other products to support people living with HIV or hepatitis C. Every month Buyers Club provides food security for an average of 150 people. For the dinner and discussion, an inner circle of members gather for a dinner prepared by volunteer chefs and stimulating group discussions on various topics.

While the number of respondents are small, this project helped us understand the most important services/programs that ACCM should offer. Future plans include expanding the network of local businesses that take part in buyers club and improve the dinner and discussions by inviting experts of the topics covered.

In conclusion, Person-Generated Index (PGI) showed evidence as being a useful instrument in capturing users' needs in a community organization setting. We recommend other organizations to implement the PGI and further test it with a larger sample. The reason for low response rate could stem from to the absence of digital member directory. In fact, this project helped us recognize the urgent need of digitalizing the contact information of our members and continuously updating them in order to maintain an active and effective communication.