



Positively Speaking – A Podcast Exploring the Experiences of People Living with HIV/AIDS

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Note: Click on the audio buttons for supplementary information



What is “Positively Speaking”?

Positively Speaking is a 6-episode podcast that was developed by [Casey House](http://CaseyHouse.org), Canada’s first and only stand-alone hospital for people living with HIV/AIDS. It was developed by Casey House staff and clients in partnership with Ryerson University RTA School of Media in Toronto.

Here’s a clip of Muluba from Episode 1, “HIV and long-term survivors”:



Why a Podcast?

The podcast medium was seen as an ideal platform for a healthcare organization to work in partnership with clients, give voice to people’s lived experience, address stigma and build community.

Who is it for?

The podcast was created primarily for people living with or affected by HIV/AIDS and for a wider audience who would benefit from listening to and reflecting on the content.

The Inspiration

- Inspired by [Ear Hustle](http://EarHustle.com)
- Hugely successful, powerful, innovative podcast out of San Quentin prison
- Shows life inside prison through personal narratives



Guiding Principles

- Recognizing the power of narrative – engaging people living with HIV/AIDS to share their experiences
- Participation
- Validating experience
- Community-building
- Reaching a broader audience
- Challenging HIV/AIDS stigma
- GIPA/MEPA



Client Engagement

- All Casey House clients were invited to attend an initial meeting to discuss the idea and test out interest
- Great response – enthusiasm about developing a podcast, about participating and sharing personal stories
- Brainstormed ideas for podcast themes
- 22 themes identified
- Each participant received an honorarium

Dotmocracy

The 22 themes were displayed in a common area and clients and staff were given 6 adhesive dots to post beside their favourite themes. The 6 with the most votes were used as the themes for the first season.

- Long-term Survivors
- HIV and Relationships
- HIV and Mental Health
- HIV and Housing
- HIV and Isolation
- Living Positively with HIV



The Process

The podcast was produced at Casey House with Casey House clients. A total of 43 participated in the client engagement sessions, the advisory committee, and as interview subjects in the podcast.

Staff Team

3 staff worked as a team to lead the entire process.



Client/Community Collaboration

Client Engagement led to the development of a 15-member Advisory Committee.

- Met twice a month.
- Provided guidance on the topics for each episode.
- Some committee members were also guests on the podcast.
- Total of 27 clients were guests on the podcast for Season 1.
- Each member was paid an honorarium.
- Listening sessions, open to all clients, were held after each episode aired. Attendance was always high, feedback positive
- Prior to the official launch we held an appreciation event with all the clients who participated in the podcast development.



Time Frame

September 2018 – December 2019

Ethical Considerations

- Confidentiality – it was critical that participants understood and were comfortable that the podcast would be part of the public domain.
- Consent- careful attention was given to utilizing the organization’s consent form and process.
- Diversity – substantial consideration was given to diversity and the politics of inclusion/exclusion in the selection of participants.

The Production Process:



Lessons Learned

Learning curve

Partnering with Ryerson RTA School of Media allowed us to develop our technical skills and the art of podcasting.

Impact/Unanticipated Outcomes

We under-estimated the degree of validation that people experienced from the opportunity to participate and the therapeutic value of sharing their stories.

Practice

We needed a lot of time to familiarize ourselves with the equipment.

Time

Creating, writing, producing a podcast, especially when it’s a new skill, takes a lot of time.

Flexibility

We had to be open to make changes along the way:

- Client participation:** Our client engagement sessions initially were weekly and open to anyone interested. This meant orienting new members frequently, which interrupted the focus and pace of the process and undermined group cohesion.
- Hosting:** We initially planned on having two hosts but based on Ryerson’s advice we switched to one.
- Recording on home ground:** Initially we conducted some interviews in the studio at Ryerson, based on the facilities and technicians on-site.
- Consistent Interviewer:** When we shifted from two hosts to one, we divided roles to have one team member conduct all of the interviews, except when the host had a close relationship with a specific client.
- Single interviews:** We also realized that interviewing one guest at a time allowed for a safer and more comfortable environment for our client’s to tell their stories.



Conclusions

The creation and production of the Positively Speaking podcast at Casey House Hospital: -

- Powerfully and positively impacted the clients who were interviewed.
- Strengthened the connection between clients and Casey House Hospital.
- Was an effective collaborative community initiative.
- Contributed to Casey House’s commitment to community building.
- Was a highly effective medium to tell people’s stories.
- Was more time consuming and challenging to produce than expected, but the benefits justified the efforts and investment.
- Although most of the topics in the podcast were about challenges that people faced, we deliberately ended each episode on a positive note

Here’s a clip of Robert from Episode 6, “Living Positively With HIV”:

Next Steps

- Casey House will continue to support the development of future seasons of the podcast.
- Learnings from Season 1 will be applied to Season 2.
- New formats will be explored (e.g. one guest per episode, more website content and use of social media).
- As of June 1st, 2020 we have been working on season 2: we have recorded 2 interviews: -

- An HIV+ man two days prior to his medically assisted death;
- A young refugee describing his experiences living with HIV.

Acknowledgments

- The advisory committee
- All clients, guests and community members who participated
- Casey House board, senior team, staff and volunteers
- Nick Nausbaum (composer)
- Ryerson RTA School of Media
- David Matta, Audio Engineer
- Garret Barlow and Tony Boston (volunteers)
- All listeners and supporters
- Ear Hustle from Radiotopia – the inspiration!

Positively Speaking can be found on your favourite podcast platform, or scan the QR code below for a link to Positively Speaking on the Casey House website. You can reach us at <podcast@caseyhouse.ca>

