

Psilocybin-Assisted Therapy Engagement

REPORTING ON WHAT WE HEARD

May 2022



INTRODUCTION

Patients play a key role in advocating for increased access and awareness of Psilocybin-Assisted Therapy (PAT). Patients also help to advance the scientific evidence base of this therapy by participating in research studies. What we know less about is the extent to which patients actively contribute to the development of PAT research, ensuring studies address their priorities, needs, and concerns.

Traditionally, health research has involved patient and public perspectives as study participants; answering a survey, joining focus groups, or doing a 1-on-1 interview. Patients are also included in health research trials or experiments as research subjects (for example, clinical trials).

Patient-Oriented Research (POR) moves health research away from being done “on” or “for” patients. Instead, POR focuses on doing research “by” and “with” patients. What this shift looks like is patients and public joining research teams as advisors; collaborating with researchers on the topic, scope, design, conduct, and of research projects.

A Victoria, BC-based team of clinicians and end-of-life specialists; alongside partners from TheraPsil - a non-profit patient advocacy organization - and Victoria Hospice, are interested in generating evidence that explores the use of psilocybin in the compassionate treatment of end-of-life emotional distress. They want to ensure that their future research activities accurately reflect the lived experiences, concerns, and needs of patients. A broad engagement initiative was launched to listen and learn from those who have experience or are considering PAT for their end-of-life emotional distress.

This public report captures a snapshot of what was heard as a result of the team's engagement efforts. If you would like to discuss the full engagement initiative, please contact the BC SUPPORT Unit Island Centre (islandcentre@islandhealth.ca).

WHAT WE DID

The purpose of the engagement initiative was to listen and learn from those who have either received Psilocybin-Assisted Therapy (PAT) for the treatment of their end-of-life emotional distress ('Patients'/P) or those who are curious/considering PAT ('Curious Patients'/CP).

Engagement planning and design was guided by best practices in Patient-Oriented Research (POR) and public engagement from leading organizations including the BC SUPPORT Unit and the International Association for Public Participation.

With the goal of creating a low-barrier, non-intrusive engagement opportunity - giving respondents the chance to engage at a time and space of their choice - an online survey was designed. The survey ran November 1st, 2022 - January 31st, 2022 and was shared across the PAT community.

The survey focused on identifying:

- challenges and supports to PAT
- priority patient experiences
- the stages of PAT where patients had the most unanswered or outstanding questions.
- patient priorities for future Patient-Oriented Research

A total of 27 respondents completed the engagement survey; **seven** identified as having experience with receiving PAT (P) and **twenty** identified as someone considering PAT (CP). The only demographic similarity between these two groups is that the majority of them were over 60 years old. There were differences in gender and location of residence between the two groups.



53% Male

57% over 60 years old

58% living in BC



60% female; 5% Non-binary; 5% Two-Spirit

65% over 60 years old

55% living outside BC

WHAT WE HEARD

In January 2022, Health Canada made changes to how individuals access PAT. At the time of the survey development and launch, acquiring a Section 56 exemption* was the only legal way to access PAT. This survey captures feedback **before** the Health Canada PAT access changes.

This survey was also conducted via an open link that was accessible to anyone. These findings provide a window of insights into perceptions of those who participated in the survey and do not reflect the opinions of anyone but this group. Survey questions available [here](#).



Challenges

On a scale of 1 to 5, respondents were asked to indicate how big a list of challenges were or might be to them. The matrix-structured question used a 5 point Likert scale with 1 being not at all a challenge and 5 being a very big challenge.

The top challenges for patients were the **cost of treatment**, **acquiring a Section 56 exemption**, and the **fear of having a bad trip/experience**.

Curious patients perceived the biggest challenges associated with PAT to be **acquiring the exemption**, the **lack of support from a healthcare provider (HCP)**, and **acquiring the psilocybin**.



Supports

To learn more about the topic of supports, we asked respondents to indicate on a scale of 1 to 5, how helpful a list of supports were or might be to them. A rank of 5 meant the support was very helpful and 1 not at all helpful.

The top supports for both groups included the **help of an organization to support their application to request a Section 56 exemption** and **support from a HCP** (e.g., physician, psychologist, counsellor).

Patients also highlighted **financial support** as a top support; while curious patients perceived the **help of an organization to connect them with a trained HCP** as being a top support.

* Section 56(1) is a piece of legislation in the Canadian Drug & Substances Act. It states that the Minister of Health can allow the use of prohibited therapies (such as psilocybin) if, in his or her opinion, such an exemption is necessary for a medical or scientific purpose or is otherwise in the public interest. As of January 5th, 2022, Health Canada now requires all patients who are in need of medical access to psilocybin, for a serious or life-threatening illness, to first either access a clinical trial and/or attempt access through the Special Access Program (SAP). Health Canada is no longer accepting section 56 applications “unless it can be demonstrated that access to psilocybin was not possible through existing legal routes”.

WHAT WE HEARD



Patient Experiences

Respondents were asked to indicate how important 11 different types of patient experiences were to them, where 1 meant not at all important and 5, very important. Examples of the kinds of patient experiences respondents were asked to rank included things like: The importance of receiving respectful and culturally safe treatment by the HCP; receiving clear information from the HCP; and Safety (no additional harm to patients).

For patients who have received PAT, the most important patient experiences were having **support from an HCP post-Psilocybin session** to help with integration; **receiving clear information from the HCP**, and **access to a safe source of psilocybin**.

Curious patients ranked a **reduction of end-of-life distress symptoms** and **spiritual/existential health** as being the most important patient experiences.



Unanswered Questions

There are five main stages or steps in PAT:

- Education (learning about the treatment to inform your decision)
- Pre-Psilocybin session (acquiring a Section 56 exemption and connecting with an HCP)
- Sourcing Psilocybin
- The Psilocybin session itself
- Post-Psilocybin session (discussing experiences and planning integration with the HCP)

To help identify where there may be information gaps around PAT, respondents were asked to rank the stages of treatment where they had the most unanswered questions where 1 meant the most and 5 the least.

Patients had the most unanswered questions in the **earlier stages** of the treatment (information to support making an informed decision about treatment; acquiring the exemption; and sourcing the psilocybin).

Curious patients had unanswered questions that span across **all treatment stages**, including pre-session, the session itself, and post-session.

WHAT WE HEARD



Future research priorities

The last topic the team was interested in learning more about was future research priorities. Both patients and curious patients were asked about the most important aspects of PAT that research should explore next. The question was open text, allowing respondents to take their answers in whichever direction they wanted.

Patients who had experienced PAT were most interested in future research that explores experiences of the psilocybin session itself.

"The experience MUST be personalized to the individual. If the therapy is provided in a group setting, the individual must be given an option to experience the psilocybin with privacy."

"The variety of experiences one could have."

Curious patients had a much broader range of topics they thought future research should explore. There was interest in the physiological aspects of the therapy; the effectiveness of the treatment on distress and depression; the connection between the treatment and spirituality; and lastly the impact the treatment has on an individual's overall health and wellness.

"How [psilocybin] changes the physiology of the brain."

"How long the effects last and if boosters are needed; any side effects?"

"The benefits of providing a reduction in fear or depression."

"The relationship between [psilocybin], spirituality, and mental health."

"The impact on individuals' feelings of wellbeing."

NEXT STEPS

No. 01 – Sharing broadly

This public report was co-developed by the BC SUPPORT Unit Island Centre and team members. It has been made available through TheraPsil, Victoria Hospice, Island Health, and BC SUPPORT Unit channels. Please share it!

No. 02 – Building a POR team

To move this engagement work forward, the team is looking to connect with academic and clinical researchers in BC who have an interest in Psychedelic Medicine; Patient Partners who have experience of/considering PAT; and healthcare system policy makers. Want to join the conversation or learn more? Contact us (islandcentre@islandhealth.ca)!

No. 03 – Informing care

One of the many goals of this engagement work is to inform research design and eventually health service design, including the integration of PAT in healthcare settings. Keeping healthcare system leadership and decision makers informed of activities is an important component of the work done to date and future work to come.

THANK YOU

Thank you to all of the individuals who took the time to share their feedback. Your insights have helped to explore knowledge gaps across the Psilocybin-Assisted Therapy treatment process and will help chart the future of psilocybin-assisted therapy research.

CONTACT US



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