



THE UNIVERSITY OF
SYDNEY

STELLER

**Supporting the Translation into
Everyday Life of Lived Experience
Research**

**SUMMARY
REPORT**

MARCH
2020

Summary of Results

Thank you again for participating in the STELLER study and for sharing your experiences. This was a collaborative project between researchers with and without lived experience of mental health issues and peer workers. Its purpose was to explore the translation and usefulness of lived-experience research in the lives of people living with mental distress. While we were unable to locate research about consumer use of lived-experience research, our collective experience has indicated that many consumers who are not themselves involved in collaborative research do not even know that it exists, let alone how to access the findings. Little is known about how useful consumers might find lived-experience research, or what the best formats are to bring it to their attention.

Your contribution is very much appreciated. The importance of consumers being involved in mental health research is increasingly being recognised as critical. During your interview you indicated that you would like to receive a summary of what we found. Please read through this information and let us know if the findings are similar to what you experienced or if you have anything else to add.

We interviewed 38 consumers. Most of you stated that you have been living with your mental health issues for over 10 years and it was not uncommon to have been given multiple diagnoses over that time.

The STELLER Team:

Anne Honey, Katherine Boydell,
Francesca Coniglio, Leonie Dunn, Kate Gill,
Helen Glover, Monique Hines,
Justin Scanlan, Barbara Tooth.

Our Peer Workers:

Alise Blayney, Nathan Clissold, Candice Fuller,
Darren Wagner, Cheryl Wittingslow.

Our Summer Scholarship student:

Trang Do





*I felt positive about the fact that someone gave a sh*t enough to ask someone with lived experience what they thought ... I felt a good feeling at the end.*



Overall experience with the program

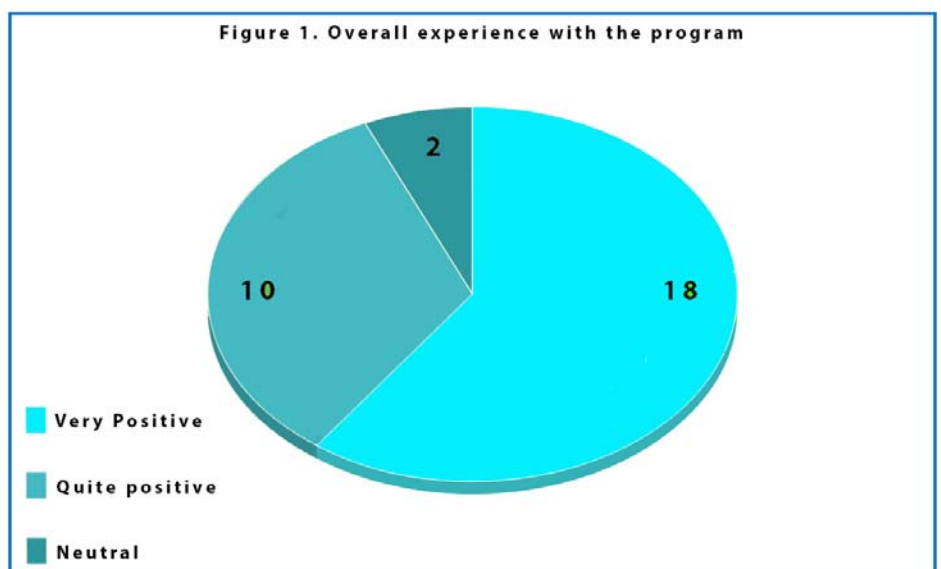
You reported high levels of satisfaction with the program overall, with 93% of of you describing your experience as “quite positive” or “very positive” (Figure 1). Half of you shared your knowledge of lived experience research with other people. One participant talked about using material from the resources to help others and said:

“I also share with other people because I help people that have challenges in their life... So, I incorporate some things into it to help”.

We wanted to know whether exposure to lived-experience research increases hopefulness. Many of you described how interacting with the resources made you feel more hopeful, positive and empowered.

When we measured hope, we discovered that levels of hope improved but not immediately after engaging with the resources, suggesting that the impact may be gradual in taking effect.

Figure 1. Overall experience with the program



The Resources

You were asked in the interviews which resources you liked most and least and your answers were diverse. The hope box was rated as favourite by the largest percentage of those who chose it. Many of you commented on appreciating the variety in the format of resources so that a diversity of needs were catered for:

"I liked the idea of different formats because everyone learns differently and if you do one particular format, you're going to miss certain people's learning experiences".

Overall, you each had quite different experiences engaging with the resources. In the vast majority of cases those experiences were positive. For example, for each resource, 60 to 80% of you said it had made an improvement in your lives. You described impacts such as being motivated to take positive action; enjoying the experience; gaining new knowledge; reflecting on your own journey, experiencing hope and empowerment, thinking more constructively about mental health issues, feeling less alone and being better able to explain mental health to other people. However, some of you had negative experiences.

Six of you showed resources to your relatives, one participant commented that she felt her mother had gained some insight about her condition from the resources. Others simply commented that their relatives also liked the resources, or that they discussed them together.

The resources were originally conceptualized as 'stand-alone', with peer workers simply bringing them to participants' attention. It was clear from the data that peer workers' interactions around the resources were critical to participants gaining optimum benefit from them.



Very inspiring hearing all the things about meaningful activities, and, identity, and recovery, and just to hear all and see it all written down on the paper and all that sort of stuff.

I could relate



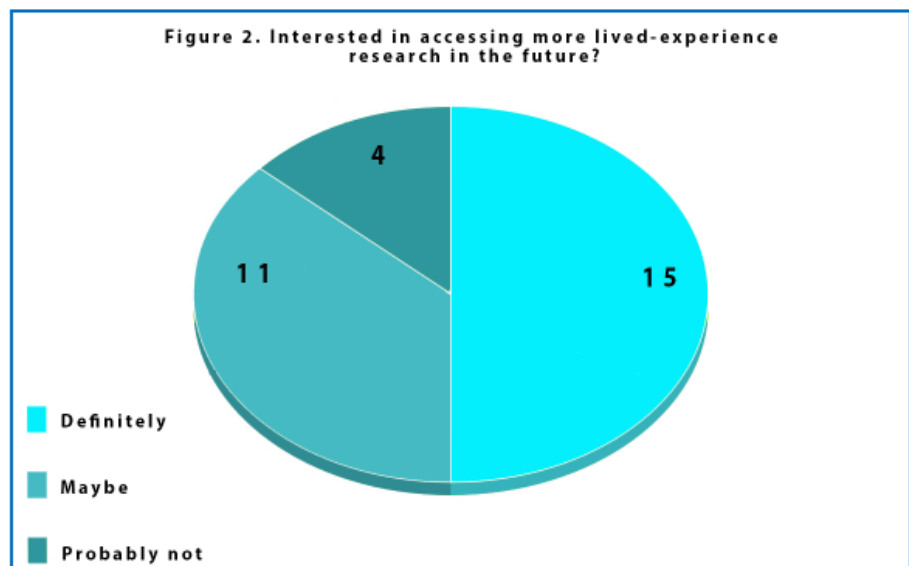
Conclusion

The STELLER research study translated findings from six lived-experience research studies into user-friendly formats and disseminated these via peer workers. While you each had quite different experiences with the resources your overall feedback was extremely positive. The study suggests that disseminating lived-experience research has the potential to be an important resource for individuals living with mental health challenges. You also suggested additional content for future research including topics around: mental health self care; life skills; and mental health conditions. You also recommended additional resource formats such as: arts-based formats, interactive activities, video and tactile formats.

When you were asked about whether you wanted to engage with more lived experience research resources in the future most of you stated that you possibly or definitely would (Figure 2). We recommend that more research is needed to assess the usefulness of lived-experience research resources in the day-to-day practice of peer workers and the impact of these resources on a larger number of diverse consumers. It will be important to distinguish the impact of lived experience resources from the impact of being in a research project.

Finally, a number of you expressed the hope that the STELLER project would continue into the future:

"I just hope something, you guys are able to elaborate on, give more of it, the research, to people. I think it's really good, because it could save someone's life. So, I just think, just keep going with it"



We hope that the findings of our study will contribute to developing improved resources to help support persons living with mental health challenges and distress.



If you have any questions, feedback or would like a copy of the full report please contact Anne Honey on:



(02) 9351 9370



anne.honey@sydney.edu.au



stellerhub.com

