# ABSTRACT

**Objective:** To identify service user research priorities and preferences outside of traditional clinical treatments and promote best practice advocacy efforts for the continued communication of these priorities.

**Setting Design:** Descriptive research – Internet-based surveys deployed via email. The first study (Fall 2018) was hosted via Survey Monkey, the second (winter 2019) and hosted on Logic Depot systems. Surveys were both multi-punch and short response. Surveys were developed and distributed in collaboration with existing national networks that support peer specialists, provide technical assistance to consumer organizations, or advocate on behalf of mental health and addiction service users.

**Participant eligibility criteria:** Participants were able to self-identify as being a part of the Recovery Movement, being a person living with SMI/SUD/or Neuro Diversity.

**Results:** 8 studies were reviewed, and 2 research studies conducted (study 1: fall 2018/37 respondents | study 2: winter 2019/212 respondents). Comparative analysis done on research results. First study was done with a limited amount of participants that were identified as professional advocates. This set of questions was formulated around funding/promotion / and balancing harms vs benefits. Second study included respondents from a wider population of service users, advocates, caretakers, and mental health workers that identify as members of the Recovery Movement. The initial study concluded that the top priority of advocates is that more research should be done to provide funding mechanisms to pay for peer support (77%) with more recent studies on peer support effectiveness coming in second (57%). Winter 2019 Study finds a majority of service users are interested in research on recovery support groups, effective therapies, and creative outlets as therapies.

**Conclusions:** This study showed the overall research priorities. It also allowed for comparative analysis between the groups of caretakers/advocates / and end-users. We found that advocates are not wholly in touch with what end users want and there is a need for better Community Engagement training for them to adequately represent the consumer voice. One of the main issues with this is that often advocates are often consumers, so they rely on their own voice as if it was the voice of the entire movement. Distinction must be made between the story of the advocate and the story/needs/wants of the movement. The second study indicates that Advocates and Service Users may agree on the most important need however the two diverge across the rest with advocate responses showing little variance (all things are needed) and Service Users leaning towards prioritization.

Due to the nature of the Recovery Movement and the historical lack of patient/service user input into traditional medical practice, the responses that we received from the second study (85% service users) showed small differential between preferences and was almost even across the board proving the necessity for more research in all areas. To increase patient-centeredness in decisions involving research, further research and advocacy efforts with solid community engagement science for a larger sample, and for a larger number of conditions should be undertaken.

# SURVEY METHODS

An initial multi-punch survey of Recovery Movement Leaders was completed in Fall 2018 with 37 respondents. The survey was distributed electronically via email and social media channels to potential participants that were previously identified as Recovery Movement leaders. Since the Recovery Movement remains largely undefined as a group, Recovery Movement Leaders are defined as people who serve as an advocate (with or without compensation) who believe in the principles of the movement. This survey was promoted by advocates who have access to followers as leaders within the Recovery Movement.

Winter 2019 Poetry for Personal Power partnered with Logic Depot to create a survey platform to collect data from Recovery Movement members who are primarily service-users nation-wide. The survey was distributed to 3579 potential participants via email list, CRO/RCO distribution network, and advocates. Distribution composition 96% Service Users (this number included those that do not have diagnoses and seek alternative forms of treatment to aid with recovery from mental health issues and/or trauma), 2% Advocate (non-related/paid/volunteer), 1% Service Delivery (works in behavioral health or with people that have substance abuse or addictive disorders), 1% Family/Caretaker. From that population a sample of 212 participants.

This data was compiled; the top 3 overall research priorities in the categories of substance use addiction recovery, neurodiversity, and mental health addiction recovery were identified. We incorporated those research priorities into the researcher toolkit for distribution to those who are planning and creating future research and to inform funders. We also analyzed the priorities between the groups of participants (advocates vs service users) to see if and where their interest aligned.

# RECOVERY MOVEMENT RESEARCH PRIORITIES

By Julianna Sellers, Sheri Hall, Aja Owens, and Deborah Wilcox Poetry for Personal Power funded by PCORI (Patient-Centered Outcomes Research Institute)

# SURVEY 1 - FALL 2018 RESULTS

Respondents were asked a follow-up to identify what specific needs were needing to be addressed by research. 2 gave written responses that fell within the "wellness" threshold.

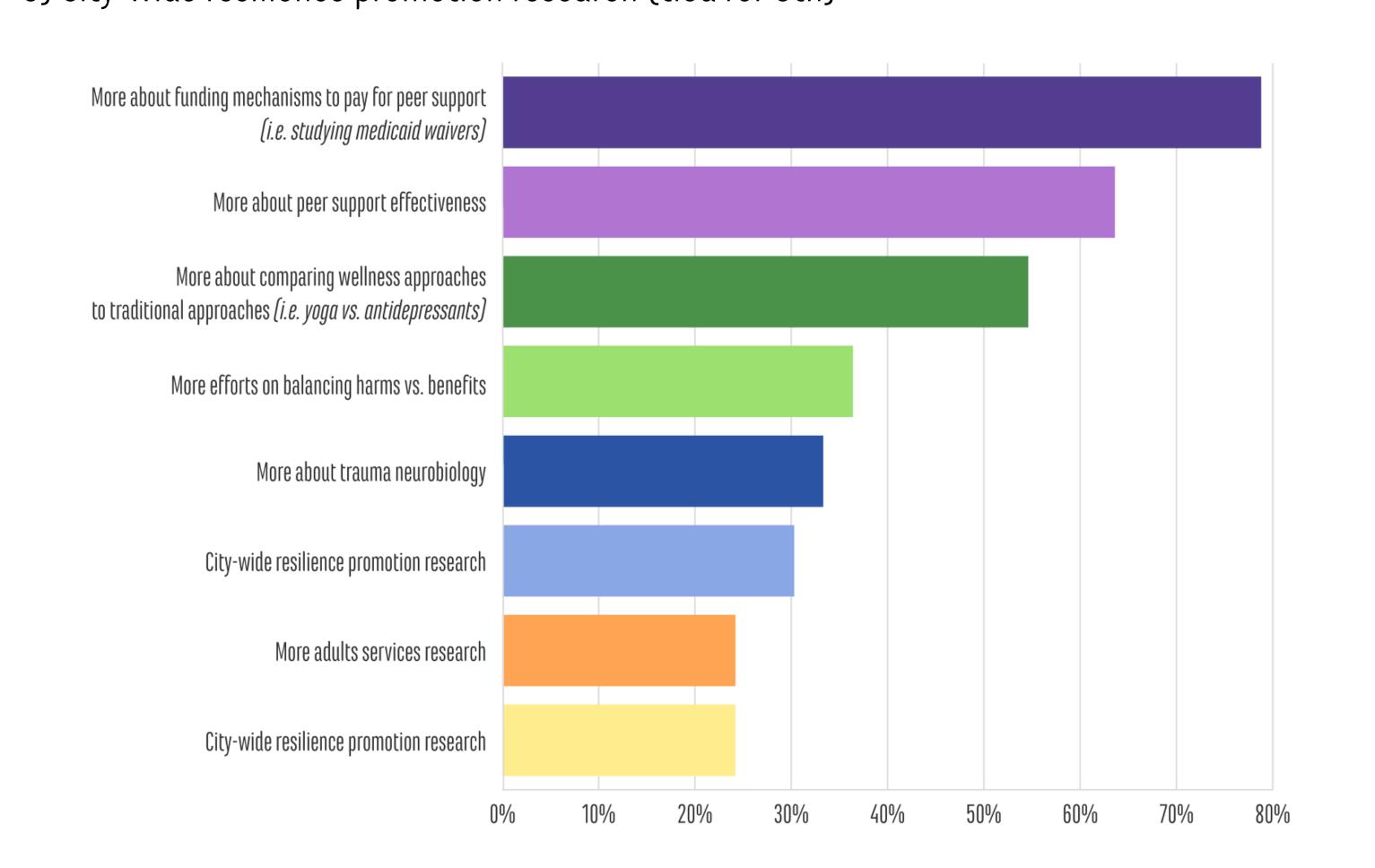
R1 "Holistic mental wellness methods. Stop negatively labeling people. Nutrition. Physical care. Maslow's hierarchy of needs. Consumer driven task forces."

R2 "Connecting with nature (gardening, animal Care, conservation, hunting, camping, etc) to reduce symptoms and increase self reliance."

Q: What are your current research priorities for academic researchers?

#### Top six responses:

- 1) More about funding mechanisms to pay for peer support (le studying Medicaid waivers)
- 2) More about peer support effectiveness
- 3) More about comparing wellness approaches to traditional approaches (ie yoga vs. Antidepressants)
- 4) More efforts on balancing harms vs. benefits
- 5) More about trauma neurobiology (tied for 5th)
- 5) City-wide resilience promotion research (tied for 5th)



Q: "What is the most important action that Peer advocates can take to address health equity?"

## Top six responses:

- 1) Promote peer support
- 2) Promote trauma-informed care
- 3) Advocate for housing, food, income, and basic needs supports
- 4) Integrate behavioral health and physical health
- 5) Policy change or legal work
- 6) Address social determinants of health

Respondents also gave follow up written responses to this question to further elaborate on what they meant and why they needed these groups to know about the Recovery Movement.

R7 "I think that any kind of reform of this broken system is going to have to start with the people in recovery and the general public who don't know how or where to find the support that they need for emotional distress and mental wellness."

R9 "General Public - Most don't know that a Community Mental Health Center exists in their community and it provides Substance Use services Many don't know that there are so many people who utilize both in our community"

R20 "People in recovery, and consumer networks (including medical patient networks, ie MS and other chronic conditions), who can start banging on the foundations and the public officials to raise the profile of Recovery Movement and Health Equity actions with the general public. It's all connected"

Q: "Who needs to know more about the Recovery Movement and Health Equity in your state?"

### Top six responses:

- 1) The general public
- 2) Elected Public Officials
- 2) People in Recovery from mental health labels or addiction issues
- 3) Mental Health advocacy organizations
- 4) Peer Run organizations
- 5) Provider Advocacy groups
- 6) Health Foundations

# SURVEY 2 - WINTER 2019 RESULTS



Recovery support groups



versus medication (tied for 4th)

Wellness approaches versus tradition models, for example yoga



\_\_ The mind/body connection and occurrences of misdiagnosis for example a mental health diagnosis for a physical ailment

#### Written in suggestions included:



"I would like to see research on veterans recovery from addiction and subscription in the military."

"Prevention efforts that help people identify what life events can lead to the need for protection of their mental health status."

"What helps people stabilize and get their life back? How many people feel they are being listened to and supported by clinicians? What can we do outside of clinical spaces to help people? Can we help families and people in treatment support one another?"

#### **TOP RESEARCH PRIORITIES FOR NEURODIVERSITY:**



Effective therapies/sensory regulation techniques

\ccommodations that help with functionality (tied for 3rd)



effects (tied for 3rd)

Medications that we are given and long term studies on their



Wellness approaches versus traditional models, for example yoga versus medication (tied for 4th)



Adapting environments to support a wider variety of brain functionality (tied for 4th)

#### Written in suggestions included:



"**PRIORITIZE** these. Additionally, neurodiversity is much more than autism. Start asking about stigma in growing up with disability. It's ignored in ACEs."



# MENTAL HEALTH RECOVERY RESEARCH PRIORITIES



Art, music, writing, and other creative outlets as therapy



Alternative/non-clinical models for mental health



example a mental health diagnosis for a physical ailment



Wellness approaches versus traditional models, for example yoga versus medication



#### What does a successful recovery life include:

"Sounds cliche but the truth is that for me, successful recovery is progress and comfort-ability in the 4 domains that have been identified: Health, Home, Community, Purpose."

"I feel recovery is an individual journey. For myself, I work to keep my independence but if I need more support them I will advocate for what I need. I feel voice is very powerful and we are all experts in what we believe would be helpful to us. We should have options because options and choice are empowerment. I feel it helps people to be understood so Peer work is very valid in the process of recovery for all individuals."

"I feel the greatest skills is giving people their own voice and educating those people how to be their own advocate. Role playing with people to help them find their words and give honest feedback to help Teaching and supporting others in how to be their own advocate help to foster independence. Again, they are their own expert in what they need and advocacy is strongest when it is from the self."

"Successful recovery is when an individual can live life to the best of their ability while accepting help, living as independently as possible, in the community, holding personal responsibility, regardless of any stereotype or stigma."

"Not feeling alone. Not feeling like you are a burden. Not wishing the paramedics had been slower. Feeling that there are people who understand. Being able to talk openly, not hiding."

"Not that mental illness experiences are normalized, but the feelings the individual experiences are part of the human experience, and the individual can become a part of society as their own individual."

## COMMUNITY ENGAGEMENT SCIENCE

- Learning how and when to include the population being studied
- Nothing about us without us!

meetings and events.

- We trained advocates to participate in coalitions, conferences, and completed multiple Community Engagement practices.
- Community Engagement can and must be improved, service users must be involved before decisions are made and programs are developed.
- Tokenizing community representatives is counter productive, traumatic, and reduces chances and apportunity for meaningful future engagement
- and opportunity for meaningful future engagement.
  Advocates may struggle with finding out who else is involved and getting invites to important
- Organizations may work in silos and be unaware of the activities of other groups and organizations.
- Stakeholders, researchers, advocates, and service users can come together and learn from one another.
- Creating real prosperity means including everyone. Future success requires the contributions of all citizens, including the ones that often go unheard.
- · Allowing the inclusion of multiple forms of expertise expands innovation.
- Community members and people with direct, lived experience of mental health and other conditions know vital information and have direct access to knowledge about life and recovery, but are rarely included as research partners.
- · Improving community engagement also expands the sphere of influence.
- Well planned and intentional community engagement comes in the form of trained facilitators, room on the agenda for all, stipends for advocates (experienced advocates as well as novices), input methods outside of meetings, training for community advocates, and community action as a result.
- The inclusion of people with lived experience is not a "favor," it is an expectation and burgeoning standard.
- Community members often call for greater relevance and connection of science to their every-day lives and neighborhoods. Participatory research represents a direct way to foster both, through greater incorporation of community input, cultural diversity, and local ingenuity.

## CONCLUSIONS

- This study is just the beginning, more research is needed that is aimed at service users.
- A challenge is to bridge the gap between research results, and meaningful long-term change.
- Thank you to PCORI for funding innovative, patient centered research.
- Funding for prevention, recovery, services, and other patient priorities are necessary to make Behavioral Health more innovative and effective.
- A major success from this project is the innovation of Story Circles. They provide a powerful tool for systems change by producing Wellness and Recovery Groups for researchers, service providers, and service users to connect on a human level through stories without the usual power dynamics.
- Allowing service users and advocates to provide input in multiple ways was paramount. Addressing accessibility and access issues were vital to reaching more people and allowing their voices to be heard.
- New research can be done to explore unanswered questions and target those areas that have been traditionally less studied in mental health research.
- · Reframe questions and shift focus from effective treatments to creating and sustaining wellbeing.
- The broader the field of research becomes into wellness methods, the more it benefits everyone.
- Start by talking to people in recovery, listen to what is and isn't working, and find out what is important to them.
  We are happy to find ways to partner with anyone committed to increasing wellness within in-
- dividuals and communities.

   Please don't hesitate to reach out if you would like to involve our community and increase col-
- laborative research into the priorities identified by members of the Recovery Movement.

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