The University of Texas at Austin
Texas Institute for Excellence in Mental Health
School of Social Work

PIR Participatory Research Workgroup: Recovery Assessments

A workgroup utilizing participatory research processes to engage peer specialists in research to enhance research practice.

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The Peer Specialists listed provided permission to include their names. Four other contributed to the process, however no permission to include names was obtained.

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Background and Purpose

Traditionally, researchers in the field of social science observed human behaviors in an attempt to assign meaning and create understanding of the human experience. Researchers intended to make contributions to the knowledge base to address challenges that prevent individuals from living their lives to their fullest desired potential. More and more, social science researchers understand that meaning should be created in collaboration with those individuals who were previously observed. When studying the experiences of individuals living with a mental health diagnosis, it is crucial that researchers involve individuals with these experiences in the processes of research (Wallcraft & Nettle, 2009). The involvement of people who utilize services for the treatment of mental health diagnoses is an empowering approach that will improve mental health research quality, utility, and relevance, provide opportunities for service users to define priorities in research, and ensure that the rights of service users are protected (Faulkner, 2009) Participatory research exists as a framework to guide researchers in a collaborative process of involving individuals traditionally considered to be participants in research processes (Baum, MacDougall, & Smith, 2006).

The Texas Institute for Excellence in Mental Health (TIEMH), an institute in the Center for Social Work Research at the University of Texas at Austin, organized two Participatory Research Workgroups involving peer support providers from the Central Texas area. Peer support providers are people in recovery from mental health challenges who are trained to share their stories to assist others in recovery. TIEMH evaluates projects and measures the outcomes of individuals working with peer specialists and change in recovery oriented practices. Involving non-researcher, peer support providers in this workgroup provided practice based consultation, influencing the viewpoint of the researchers.

Funded through a contract with the Texas Department of State Health Services (DSHS), the purpose of this workgroup was to:

- Educate peer consultants regarding the methods and process of survey development and testing and the researcher experiences utilizing survey tools.
- Engage the peer consultants in the examination of two survey tools: one intended to measure the recovery of individuals and the other intended to measure the recovery orientation of services at organizations.
- With the peer support providers' consultation, create new understanding of the tools and how the tools may, or may not, measure what they should according to your experience as a person in recovery and your work as a peer support provider.
- Provide feedback about the use of these surveys, use of surveys in general,

Method

Consultant-Participants and Design

Sixteen peer providers were invited to participate in two separate 1½-day workgroup sessions held in Austin and San Antonio, Texas in April 2015. Invitees were employees of Local Mental Health Authorities, State Hospitals, and an organization that serves people experiencing homelessness. Of the 16 invited, 13 agreed to participate (7 in Austin and 6 in San Antonio) 12 participated in the full workgroup session. Consultants were paid per day for their participation in the workgroups, which included a pre-work writing assignment.

The workgroup sessions utilized didactic, interactive, and discussion-based formats for both educational and consultative purposes. The researcher-facilitators created a PowerPoint slideshow and consultant

workbook for referencing throughout the sessions. First, the consultant-participants were introduced to the Participatory Action Research framework as well as social science and survey research concepts. Next, they learned about TIEMH researchers' specific experiences with collecting and analyzing measures of recovery and recovery orientation. Consultants were given background into the development of the two survey scales that were reviewed. Consultant-participants then assigned both quantitative and qualitative ratings to the relevance of the scale items' importance to a person's recovery based on their practice experience and personal experience with the process of recovery.

Data Collection and Analysis

Approximately one month prior to the workgroup, consultants completed a brief writing assignment that would be analyzed for discussion during the workgroup. The instructions given to consultants for the writing assignment were: "Please describe what helps in your recovery or in the recovery of the people you serve (this should not be considered a recovery story). Limit your response to approximately 250 words (about ½ page, single-spaced)." Results were analyzed using a grounded theory approach whereby codes, categories, and theoretical propositions were developed directly from the text. A researcher first read the results line-by-line and developed codes directly from the data (e.g., the code "setting and accomplishing goals" was developed from the text "setting specific goals for myself, and working towards positive outcomes has benefited [me]." Next, relationships were identified between different codes in order to develop categories of what facilitates recovery (e.g., the codes "support from friends" and "acceptance from others" were combined to form the category of social support). Finally, from these categories, theoretical propositions about what facilitates recovery were developed.

During the workgroup meetings, the consultants rated items on two validated survey tools, the Maryland Assessment of Recovery (MARS) and the Recovery Self-Assessment (RSA). The MARS measures the recovery of people with serious mental illness (Drapalski, et al., 2012). The RSA measures recovery orientation of services provided by an organization (O'Connell, Tondora, Croog, Evans, & Davidson, 2005). The participants were asked to rate how each item applies to an individual's recovery, using a scale of 1 to 5, with 5 assigning the highest value of an item to recovery. Additionally, the consultants chose 5 items from each survey which they have observed helping a person in their practice experience.

Over the course of each 1½-day session, researchers recorded discussion notes by hand as well as using a digital recorder to capture more in-depth details. A researcher condensed the recorded content into summarized notes. The researchers then analyzed the condensed recording notes and the hand written notes as findings.

Findings

Writing assignment

Analysis of the writing assignments (n=12) that asked consultants to "describe what helps in your recovery or in the recovery of the people you serve" resulted in 10 categories of what facilitates recovery. This assignment was intended as a demonstration of the process of qualitative data collection and analysis, as well as an example of how recovery-measuring instruments may be developed based on theoretical constructs that emerge from empirical data. The categories that emerged included:

- Social Support
- Holistic Well-Being
- Valuing Connection
- Personal Growth
- Self-Directed
- Peer Support
- Patience
- Strengths-Based
- Purpose/Meaning
- Hope

These tended to overlap with the Substance Abuse and Mental Health Services Administration's (SAMHSA) 10 Guiding Principles of Recovery:

- Self- Direction
- Individualized or Person Centered
- Empowerment
- Holistic
- Nonlinear
- Strengths Based
- Peer Support
- Respect
- Responsibility
- Hope

It was from the SAMHSA 10 Guiding Principles of Recovery that items on the MARS scale were developed. See *Appendix A*: What Facilitates Recovery? Codes and categories from consultant writing samples for a full list of codes contained within the categories of what facilitates recovery.

Scale items feedback

Consultants were informed that the purpose of reviewing the items was to improve upon the current scales being used rather than to completely re-write them. To that end, consultants rated how the MARS and RSA survey items applied to an individual's recovery on a scale of 1 to 5. The top rated items for both the MARS and the RSA are listed in ***Error! Reference source not found.*** and ***Error! Reference urce not found.***. For a complete listing of the item ratings, see *Appendix B*: Maryland Assessment of Recovery Scale (MARS) Feedback, ratings of relevance, and number of consultants as and *Appendix C*: Recovery Self-Assessment (RSA), Feedback, ratings of relevance, and number of consultants as important to recovery based on practice experience.

Table 1: Rating of how much items on the MARS apply to a person's recovery

Item #	Item	Rating
3	I believe that getting better is possible.	4.69
7	Overcoming challenges helps me to learn and grow.	4.69
25	I want to make choices for myself even if I sometimes make mistakes.	4.69
20	I know that I can make changes in my life even though I have a mental illness.	4.62
11	I am responsible for making changes in my life.	4.54

Table 2: Rating of how much items on the RSA apply to a person's recovery

Item #	Item	Rating
10	Staff believe in my ability to recover.	4.67
23	When I achieve recovery goals I am acknowledged or celebrated by staff.	4.55
24	Staff encourage me to have hope and high expectations for my recovery.	4.64
29	Staff help me to develop and plan for recovery goals.	4.55
30	Staff respect the decisions that I make about my care.	4.63

The consultants also rated each items relative to how much each item helps a person in their recovery, something that would be observed during practice or revealed from the consultant's experience with recovery. *Table 3* lists the top items selected by the consultants for the MARS survey.

Table 3: Items that help most with a person's recovery from the MARS

Item #	Item	Number of Consultants Selecting Item
3	I believe that getting better is possible.	8
25	I want to make choices for myself even if I sometimes make mistakes.	8
17	I am hopeful about the future.	6
9	It is up to me to set my own goals.	5
7	Overcoming challenges helps me to learn and grow.	4
11	I am responsible for making changes in my life.	4

Table 4 lists the items that help the most from the RSA.

Table 4: Items that most help with a person's recovery from the RSA

Item #	Item	Number of Consultants Selecting Item
1	Staff believe I should make my own life choices about things like where to live, when to work, whom to be friends with, etc.	9
10	Staff believe in my ability to recover.	9
20	I am encouraged to pursue challenges and try new things.	5
11	Staff introduce me to peers who can serve as role models or mentors.	4
17	Staff help me include people who are important to me in my recovery/ treatment planning (such as family, friends, clergy, or an employer).	4
25	Staff encourage me to have hope and high expectations for my recovery.	4

The following items from the two scales made the top selection in both for items most relevant and observed in practice experience.

MARS

- I believe that getting better is possible.
- Overcoming challenges helps me to learn and grow.
- I want to make choices for myself even if I sometimes make mistakes.
- I am responsible for making changes in my life.

RSA

- Staff believe in my ability to recover.
- Staff encourage me to have hope and high expectations for my recovery.

Survey Experiences

As a part of the discussion portion of the workgroup, consultants learned about TIEMH researchers' specific experiences with collecting and analyzing measures of recovery and recovery orientation. The consultants shared some of their own experiences, as many had previously assisted with the distribution of surveys (TIEMH and others) to people receiving services. The following summarize the consultant experiences:

- Paper surveys are preferred.
- People taking the surveys sometimes need support: they may have questions about the survey content.
- People taking the surveys want the process to have meaning/ impact.
- Staff administering the survey meet with challenges: time constraints and few staff administering the surveys can lend to burnout with process.
- Survey administration is a way to connect with the people receiving services.
- Surveys are too lengthy.

A complete list of the consultants' experiences are listed in *Appendix D: Consultants' experiences administering the surveys*

Feedback about the Workgroup Process

The researchers asked for the Consultant feedback about the workgroup processes. The following is a summary of this feedback:

- Consultants felt empowered and proud to be a valid voice in the process.
- The Consultants appreciated the process of gaining knowledge about survey development.
- The Consultants appreciated that they had opportunity to influence the researchers' understanding and work.

A full list of the consultant feedback about the workgroup process is in *Appendix E*.

Recommendations

Consultant Recommendations

Survey design and administration

The following summarizes the Consultants' insights and recommendations in regards to the design and administration of surveys:

Design

- Structure of Surveys
    - The printed font should be larger;
    - the space between the lines of text in the survey should be wider;
    - different selection options for the response choices should be created (e.g., circling the choice rather than filling in a bubble); and
    - Numbers and/or face icons for Likert items would be better than the "never" to "always" or "not at all" to "very much" continuums.

- Content of Surveys
    - Fewer questions would assure less survey fatigue for both people taking and those administering the survey;
    - Caution expressed about fewer questions as some questions may be the ones to which people connect;
    - Remove unnecessary words (prepositional phrases, examples in *Appendix B*: Maryland Assessment of Recovery Scale (MARS) Feedback, ratings of relevance, and number of consultants as and *Appendix C*: Recovery Self-Assessment (RSA), Feedback, ratings of relevance, and number of consultants as important to recovery based on practice experience ;
    - Eliminate repetitive items;
    - Eliminate or change items using stigmatizing language; and
    - Rewrite the titles to be less formal and "clinical".

Administration

- Researchers should train staff to administer the surveys to assure fidelity;
- Staff need to have at least a month to administer surveys;
- People need to understand the purpose of the survey and if it will bring about change; and
- Staff need to be utilized strategically to administer the surveys (who might be able to best connect to get the most accurate responses).

A full listing of Consultant recommendations about the design and administration of the surveys is listed in *Appendix F*.

Workgroup and research collaboration recommendations

Below is a summary Consultants gave the following insights and recommendations in regards to future workgroups / research collaborations:

Pre-Work Recommendations

- Consultants recommended that researchers ask future collaborators to administer surveys to people who receive services at their respective organizations and then discuss the experience with those individuals, then bringing this input to the group.
- Researchers should observe surveys being administered.

Workgroup Process

- More discussion time
- More structured discussion
- More time for the workgroup
- Go "around the table" and give each Consultant opportunity to offer feedback
- Diversify the group of peer specialists so that there is representation from multiple mental health service providers

A full list of the Consultants' recommendations are listed in *Appendix G*.

Researcher recommendations

Researchers offer the following recommendations and insights related to conducting a participatory research workgroups.

- A combination of structured discussion with open discussion obtains the most from the collaborators.
- Be prepared for surprises. The groups brought insights related to the language associated with recovery and recovery oriented services (i.e. the word recovery is outdated!). These insights need to be incorporated in future work.
- Be prepared for discussion to diverge from the task at hand. This relates to the complexity of the work. However, obtain permission from the participants to gently return the group to the task at hand in order to maximize time, and.
- Ask permission to record the entire discussion not just a segment. The researchers held, almost inadvertently, two discussion segments per group per survey. Researchers took diligent notes, but thorough insights should come straight from the consultant's mouths.
- An individual's recovery is not limited to their experiences in receiving services, but is a holistic life process; any survey should endeavor to measure this whole experience.

Conclusions

Participatory research provides the framework to engage authentically with people who, because of lived experience with a given situation, can provide genuine insight. TIEMH hosted a workgroup of peer support specialists focused on analyzing two survey tools that have been utilized to assess individual recovery and recovery orientation of services in an organization. The researchers at TIEMH hoped that involving the peer specialists as consultants in the workgroup would lend to more effective research design and practices focused on measuring recovery. The consultants provided these insights about the process of administering the surveys, the survey items, and the participatory workgroup:

- While the peer support providers noted that some of the items on the survey captured what applies to or helps a person through recovery, other items need to be reviewed, revised or removed. *Appendix B*: Maryland Assessment of Recovery Scale (MARS) Feedback, ratings of relevance, and number of consultants as and*Appendix C*: Recovery Self-Assessment (RSA), Feedback, ratings of relevance, and number of consultants as important to recovery based on practice experience chart the consultants' feedback.
- The nature of the recovery movement and the language used to describe this experience is evolving.
- The survey tool needs to be fluid enough to capture this change.
- The survey tools need to capture recovery not just related to the care received in the context of mental healthcare services, but in a person's whole life.
- Language used is critical: some language is associated with negative connotations of mental health, is jargon, or is "buzz word" terminology utilized by clinicians that people with lived experience with mental illness may not identify.
- The language of the sentences needs to be simple and direct.
- The language should focus on the person-centered, positive constructs of recovery or change.
- Delivery of the survey is as important as the survey tool itself: it helps to have a staff (peer or non-peer) sit with the person who will be responding to ensure all questions are answered provide clarification as needed.
- Peer specialists or other staff who administer surveys to people using services should be trained.
- Creative delivery assures engagement of the people taking the survey.
- People need to feel that their involvement in taking and administering the survey matters in their lives: results should be provided to all those involved in the survey and changes made as a result should be shared and tracked by all involved

The researchers at TIEMH learned firsthand the value of partnering with peer support staff for this effort. Researchers will endeavor to continue to engage individuals who could benefit from the research in the research processes.

Possible next steps for future collaborative research activities:

- Hold an additional workgroup to further explore possible revisions to the survey tools.
- Look at the measuring the outcomes of working with peer support providers to develop survey tools specifically designed to measure outcomes related to working with peer specialists rather than looking at a construct associated with the work (i.e. recovery).
- Involve peer providers more directly in the evaluation process.

As the movement towards more recovery oriented care evolves, Texas Institute for Excellence in Mental Health should move forward in the area of participatory research; the efforts to build collaborations to enhance the measurement of recovery efforts will take on new urgency. Collaborative research will become the efficient and ethical way to meet that need.

Appendix A: What Facilitates Recovery? Codes and categories from consultant writing samples

CATEGORIES	CODES
SOCIAL SUPPORT	
	SUPPORT AND ENCOURAGEMENT FROM FAMILY/FRIENDS/SUPPORT GROUP
	ACCEPTANCE AND UNDERSTANDING FROM FAMILY/FRIENDS/STAFF
	OTHERS BELIEVING IN ME
	STAFF BELIEVING I CAN CHANGE/HAVING HOPE FOR ME
	BEING TREATED AS A PERSON
	POSITIVE FEEDBACK/ACKNOWLEDGEMENT FROM STAFF
	STAFF TAKING A CHANCE ON ME
	REALITY CHECKING AND PROBLEM SOLVING WITH FRIENDS/COWORKERS
	POSITIVE MESSAGES FROM OTHERS
	OTHERS NOT CATASTROPHIZING
	OTHERS MODELING AND REACTING IN A HUMAN WAY
HOLISTIC WELL-BEING	
	SOBRIETY
	HEALTHY HEALTH HABITS
	CORRECT DIAGNOSIS
	CORRECT MEDICATIONS AND TAKING MEDS CONSISTENTLY
	MASSAGES
	USING CBT AND DBT SKILLS
	SELF-HELP BOOKS
	RECOVERY GROUPS
	THERAPY/COUNSELING -- INDIVIDUAL AND GROUP
	BANK OF RECOVERY TOOLS
	USING PERSONAL WELLNESS AND STRESS MANAGEMENT TOOLS/TECHNIQUES
	SPACE/CREATING SACRED SPACE
	BEING QUIET/PRESENT
	MEDITATION
	MINDFULNESS
	JOURNALING
	MUSIC AND SINGING
	THE ARTS
	SCHEDULING TIME FOR FUN/RELAXATION
VALUING CONNECTION	
	CONNECTING TO OTHERS IN DEEP WAYS
	VALUING CONNECTION
	BEING HEARD AND SEEN BY OTHERS
	SOCIALIZATION/RECOVERY TAKES PLACE IN RELATIONSHIPS WITH OTHERS
	COMMUNICATION SKILLS
	CREATING/MAINTAINING HEALTHY RELATIONSHIPS
	ENDING UNHEALTHY RELATIONSHIPS
	SETTING HEALTHY BOUNDARIES
	TRUST
	REACHING OUT FOR HELP FROM FRIENDS WHEN NEEDED
	CURIOUSITY ABOUT RELATIONSHIPS/OTHERS

PERSONAL GROWTH	
	CHANGING AND GROWING
	EXPLORING
	DOING AND LEARNING NEW THINGS
	EDUCATING SELF ABOUT MENTAL HEALTH AND TRAUMA
	HAVING AN OPEN MIND
	DISCIPLINE
	KNOWING SELF
	SELF-REFLECTION/AWARENESS
SELF-DIRECTED	
	SETTING AND WORKING TOWARDS GOALS
	BEING PROACTIVE
	PERSONAL RESPONSIBILITY
	ADVOCATING FOR SELF
	TAKING RISKS IN ORDER TO GROW
	PERSERVERENCE
	LEARNING YOU HAVE THE POWER TO CONTROL YOUR LIFE
PEER SUPPORT	
	PROVIDING PEER SUPPORT PROVIDES INSPIRATION/MOTIVATION
	HELPING OTHERS AS A WHOLE HEALTH/PEER SUPPORT SPECIALIST
	ADVOCATING FOR OTHERS
	BEING OPEN IN TELLING MY STORY
	EDUCATING OTHERS ABOUT MENTAL HEALTH
	EXPOSURE TO OTHER PERSONS IN RECOVERY INSPIRES AND INSTILLS HOPE
	WORKING IN PEER POSITION PROVIDES MEANING, PURPOSE, PERSPECTIVE, AND INFORMATION/TECHNIQUES FOR RECOVERY
	ACTIVISM (EMPOWERING THE OPPRESSED TO USE THEIR VOICES)
	SHARING STORIES TOWARDS COMMUNITY HEALING
PATIENCE	
	UNDERSTANDING THAT RECOVERY IS NOT EASY
	RECOGNIZING RECOVERY IS AN ONGOING PROCESS
	PATIENCE
	THINKING BEFORE ACTING
	ACCEPTANCE THAT THINGS DO NOT ALWAYS WORK OUT AS PLANNED
	TIME TO PROCESS AND EVALUATE THINGS
STRENGTHS-BASED	
	FOCUSING ON WHAT AN INDIVIDUAL CAN DO
	CREATING FROM HEART AND NOT FEAR
	INCREASED SELF-WORTH/BELIEVING IN SELF
	BELIEF THAT MORE THAN DIAGNOSIS
	CURIOUSITY ABOUT SELF
	MEETING AN INDIVIDUAL WHERE THEY ARE
	HAVING HIGH EXPECTATIONS FOR SELF
	IDENTITY FROM MENTALLY ILL PERSON TO PERSON WITH A MENTAL ILLNESS
	BREAKING THROUGH NEGATIVE MESSAGES THAT SOMETHING IS WRONG WITH YOU
PURPOSE/MEANING	
	PURPOSE/MEANING IN LIFE
	KEEPING BUSY
	ACTIVISM (USING VOICE TO STAND UP FOR BELIEFS)

HOPE	
	HOPE/HOPE FOR FUTURE
	MOTIVATION
	SEEING LIFE AS AN ADVENTURE

Appendix B: Maryland Assessment of Recovery Scale (MARS) Feedback, ratings of relevance, and number of consultants as important to recovery based on practice experience

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
1	I can influence important issues in my life.	• Represents construct of self-determination. • "Issues" implies stigma applied to mental health.	4.46	2
2	I have abilities that can help me reach my goals.	• "Goals" more associated with clinical objectives and not individual desires. • Suggested revision of "my goals" to "my personal goals". • Item could replace Item #5.	4.33	1
3	I believe that getting better is possible.	• "Getting better" places too much emphasis on the illness. • Suggested revision of "getting better" to "change" or "recovery".	4.69	8
4	When I have a relapse, I am sure that I can get back on track.	• "Relapse" is a stigmatizing term. • Suggested revisions: "setback" or "struggle". • Replace "when" with "if". • Overall feedback: delete and replaced with item #7 and item #25.	4.00	0
5	I have skills that help me to be successful.	• Item to be replaced by #2. • Term "successful" suggestive of external standards not internal personal standards.	4.46	2
6	My strengths are more important than my weaknesses.	• Some consultants prefer that item be eliminated. • "Weaknesses" is a stigmatizing term..	3.92	1
7	Overcoming challenges helps me to learn and grow.	• Item should remain on reduced survey and could replace item #4.	4.69	4
8	I can have a fulfilling and satisfying life.	• No recorded commentary about this item.	4.46	1
9	It is up to me to set my own goals.	• Item reflects the importance of setting your own goals, defining where you want to go. • "Goals" noted to be a buzzword, possibly associated with clinical goals, revise to "personal goals".	4.54	5

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
10	I believe I make good choices in my life.	• Some consultants prefer that item be eliminated • Phrase "good choices," stigmatizing and pejorative.	3.62	0
11	I am responsible for making changes in my life.	• Item captures power of the individual. • Relevant in situations in which a person may have choice (limited in some in-patient settings).	4.54	4
12	I feel good about myself even when others look down on my illness.	• Approaches idea of the importance of self-acceptance. • Delete the phrase "even when others look down on my illness."	3.67	0
13	I am confident that I can make positive changes in my life.	• Item captures the possibility of changes occurring, captures the important construct of hope.	4.46	2
14	I am responsible for taking care of my physical health.	• Similar to in 13, 11 or 1; delete to shorten survey.	4.46	0
15	I work hard to find ways to cope with problems in my life.	• Consultants noted that "cope" is a clinical buzz word. • Suggested revision: replace "cope with problems" with "solve problems". • Some consultants prefer that item be eliminated.	4.46	1
16	I believe that I am a strong person.	• No recorded commentary about this item.	4.15	1
17	I am hopeful about the future.	• Item should remain on reduced survey. • Item is especially important because peer supporters inspire hope.	4.38	6
18	I feel loved.	• Some consultants prefer that item be eliminated. • Discussion about the relevance of this item to recovery in the context of self-acceptance being a more important construct and self-acceptance inherently capturing this the construct of feeling loved.	4.17	2
19	I usually know what is best for me.	• Suggested revision: delete the word "usually".	3.69	1
20	I know that I can make changes in my life even though I have a mental illness.	• "Even though I have a mental illness" is stigmatizing. • Should read, "I know I can make changes in my life."	4.62	1

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
21	I am able to set my own goals in life.	• Similar to 9, but applies to different stage of recovery. • Phrase “am able” holds some ambiguity. • Suggested revision: “I set my own goals in life.”	4.54	2
22	I am optimistic that I can solve problems that I will face in the future.	• Item is a good replacement for item #4. • Suggested revision: replace “I am optimistic” with “I know”.	4.33	2
23	I can bounce back from my problems.	• Item very similar to #4 without stigmatizing language. • Item should replace item #4.	4.33	2
24	I feel accepted as who I am.	• Some consultants prefer that item be eliminated. • Discussion about the relevance of this item to recovery in the context of self-acceptance being a more important construct and self-acceptance inherently capturing this the construct of feeling accepted.	4.00	2

25	I want to make choices for myself, even if I sometimes make mistakes.	• Consultants stated this item should remain on the survey with one of two possible revisions:
		  ○ “I want to make choices myself.”
		  ○ “I want to make choices myself, even if it doesn’t work out.”
			4.69	8

Appendix C: Recovery Self-Assessment (RSA), Feedback, ratings of relevance, and number of consultants as important to recovery based on practice experience

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
1	Staff believe I should make my own life choices about things like where to live, when to work, whom to be friends with, etc.	• Choice essential to construct of recovery. • Suggested revision "Staff believe I should make my own life choices."	4.42	9
2	This organization provides options for me to choose from to include in my recovery/treatment plan.	• As worded, this item is not person centered, and emphasizes clinical options possibly selected by the organization staff. • Suggested revision: "This organization provides options for me to choose from to meet my personal goals." • Could be combined with #29.	4.25	2
3	Staff are knowledgeable about special interest groups or activities in the community.	• Knowledge of staff is less critical than staff being able to help people connect with resources. • Replace with item # 28.	4.42	0
4	Staff help me get involved in non-treatment related community activities.	• Replace with item # 28.	4.17	1
5	Staff partner with me to assess progress toward my recovery goals.	• Term "assess" clinical.. • Replace "recovery goals" with "personal goals".	4.17	1
6	Staff offer me opportunities to discuss my spiritual needs when I wish.	• Some organizations limited on ability to engage in this area. • Suggested revision: "When I wish" can be deleted.	4.00	1
7	This organization provides opportunities for me and my family or supporters to learn about recovery	• Reference to family can trigger trauma experiences.. • Defining recovery important step toward recovery.. • Suggested revision: "This organization provides opportunities for me and my supporters to learn about recovery."	4.00	1
8	I attend organization advisory boards or management meetings.	• Combine with 16 and 26. • Noted as not a priority for most receiving services. • Consolidate 8, 16 and 26 into: "This organization provides opportunities for people to be involved in planning, meetings or evaluation of services."	3.33	1

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
9	Some groups, meetings, and other services are scheduled in the evenings or on weekends to accommodate my schedule.	• Noted not to be a huge priority for people receiving services..	3.83	1
10	Staff believe in my ability to recover.	• Staff, or anyone, believing in a person is important; denotes human connection. • Suggested revision: "Staff believe in my ability to change." Or "Staff believe in my ability to move forward."	4.67	9
11	Staff introduce me to peers who can serve as role models or mentors.	• Item is ambiguous: does it refer to peer support staff or peers receiving services. • This item references connection with others.	4.42	4
12	I can change my service provider(s) when I wish.	• No recorded commentary about this item.	4.18	3
13	This organization provides educational activities in the community about mental illness or addictions.	• No recorded commentary about this item.	3.92	0
14	I received a copy of my recovery/treatment plan.	• A recovery or treatment plan is a tool to gauge progress toward goals, but the receipt of the document is a check box on a task list – relevance of the piece of paper to recovery debated.	3.75	1
15	Criteria for successfully discharging from the organization were discussed with me when I began receiving services.	• No recorded commentary about this item.	3.42	0
16	I am involved in the evaluation of this organization's programs, services, or service providers.	• Combine with 8 and 26, see revision listed with item 8.	4.08	1
17	Staff help me include people who are important to me in my recovery/treatment planning (such as family, friends, clergy, or an employer).	• People may not need – or want – to make connections due to preference or trauma. • Suggested revision: "Staff help me include people who are important to me in my personal goals."	4.33	4

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
18	Staff connect me with self-help, peer support, or consumer advocacy groups.	• Item references connection to supportive individuals with lived experience.	4.50	3
19	This organization offers services that align with my interests, culture, or life experience.	• Item is wordy, no suggested revisions.	4.33	0
20	I am encouraged to pursue challenges and try new things.	• Trying new things is important to those on a recovery journey. Helps build a person up. • The word "encouraged" is a word that connotes human connection.	4.25	5
21	The primary role of staff is to assist me with fulfilling my recovery goals.	• This item should specify "personal goals" rather than "recovery goals". Consultants noted that "recovery goals" could refer only to those goals established by staff.	4.33	3
22	Staff believe I am able to manage my symptoms.	• Item should be eliminated. This item reduces peoples' experiences to symptoms; language is stigmatizing.	4.00	0
23	When I achieve recovery goals I am acknowledged or celebrated by staff.	• Item is wordy. • Suggested revision: "Staff acknowledge or celebrate when I meet a personal goal."	4.55	3
24	Staff encourage me to have hope and high expectations for my recovery.	• "High expectations for my recovery" has stigmatizing connotations. • Suggested revision: "Staff encourage me."	4.64	4
25	Staff offer me opportunities to discuss my sexual life when I wish.	• Reference to sexual life could evoke past trauma. • Suggested revision: "Staff offer me opportunity to discuss my intimate relationships." • Most participants suggested this item could be omitted.	2.80	1
26	I help staff with the development of new groups, programs, or services.	• Combine 8 and 16, see revision listed in item 8.	4.09	1
27	Staff assist me with getting a job.	• Suggested to be another item on a check list.	4.40	1
28	Staff ask me about my interests or the things I would like to do in the community.	• Could replace # 3 and #4.	4.45	0

Item #	Item	General Comments	Relevance Rating 1 to 5	Consultants Selecting Item
29	Staff help me to develop and plan for recovery goals.	• Item represents a task on a check list. • If framed as personal goals, could be more relevant to a person's recovery.	4.55	0
30	Staff respect the decisions that I make about my care.	• Consultants expressed that this item is very important. • Suggested revision: "Staff respect my decisions."	4.63	2

Appendix D: Consultants' experiences administering the surveys

- Paper surveys are preferred as people feel intimidated by completing surveys on a computer;
- Administering surveys via a laptop computer limits administrators to only being able to have one completed at a time, contributing to quicker survey administrator burnout.
- When only a few staff are sharing the responsibility of distributing surveys, the process can become fatiguing. Consultants used the term “burnout” referencing the process of delivering multiple surveys;
- Sometimes administering surveys interview style is preferred because papers get lost;
- People sometime don’t know what some of the terms on a survey mean. People administering the survey sometimes have to explain terms, therefore having a person administer the survey helps
- Consultants noted that asking if a service task is done is less meaningful than the quality of the relationships with service providers.;
- Completing surveys with a group of people receiving services has been helpful because when people have had a question about a specific survey item, they would ask each other and come up with their own answers;
- The process of taking the survey is, in itself, doing something with people;
- One peer staff got a room of people fired up to do the survey as a group – this got them done quickly. The administrator told people it was important and explained the purpose of the survey. People felt that they were involved. People separated to do surveys, then came back together;
- Some people stop responding halfway through the survey because of its length;
- When surveys were not received by peer providers who would be administering them until close to the end of the allotted administration period, this “time crunch” resulted in limited numbers of responses; and
- Language used in surveys is very important: some words can inspire hope. Some words feed the negative feelings people may have about themselves or are words associated with “being sick”.

Appendix E: Consultants' feedback about the workgroup experience

- Getting a real grasp on the view of researchers and why surveys are the way they are. That way when I take another survey that I find disconcerting I better understand the stance of the creator of that survey.
- Collaboration from different providers on interpretation of questions on commonality and different perceptions looking at wording of questions to promote better outcomes on data and quality of life.
- Collaborating with other peers and learning from each other's ideas and outlooks on the survey questions.
- Understanding that the process is changing. Remembering how we talk or ask questions makes a difference.
- Felt heard, informal feel was comfortable, format was effective
- To be included in this research workgroup was an honor. Knowing that we have a voice, that we can make a difference.
- Learning about the continuum of participatory research, specifically being in the contribution phase, brainstorming together and giving our experiential feedback about 2 surveys (MARS and RSA)
- I think the discussion about language used in these questions was the most helpful. Language has a big influence in how individuals interpret a survey. I was glad to hear Juli say some of her perspectives changed as a result of this workshop!!
- This was fantastic. Thank you for the experience - I do feel valued and appreciate the opportunity to give input. Thank you!

Appendix F: Consultant recommendations for survey design and administration

- Regarding the length of survey scales, a longer scale may be preferred because you don't know which question applies to an individual. On the other hand, a shorter scale may instead be preferred because people get fatigued filling out surveys;
- The font used on TIEMH surveys is too small. Sometimes people had to put on their glasses to read them. The font should be enlarged;
- Any "fluff" or unnecessary words should be removed;
- Some words have become buzz words associated with mental health care and could be replaced with terms that apply more universally to a person's ability to grow and change: e.g. "recover" and "cope";
- On TIEMH surveys, the text lines are too close together such that people have trouble reading them. The lines should be spaced apart further;
- Circling a number for response choices rather than filling in a bubble may be easier for people to complete;
- "Always" or "never" are almost never appropriate response choices;
- Using numbers without words to represent response choices is better;
- A "smiley face" icon agreement scale may facilitate ease of response for some people;
- Giving people options when they get surveys such as where to take, whether to wear headphones, being able to break up the survey by taking it in different sections facilitates completion;
- Eliminating items that are repeated throughout, but worded in slightly different ways, would shorten the MARS scale to a more practical length;
- Some of the words used in the items are "negative self-talk" and should be removed so that they do not have a negative impact on the responder;
- People who administer surveys should receive feedback on the results of the surveys;
- Paper surveys are preferred as people are sometimes intimidated by computer surveys;
- Peer support should administer these types of surveys in the hospital setting, but at a community center where there are many more case managers that peer staff, case managers should also be involved;
- One month is a better administration period than two weeks, including several reminders that reach the people who are actually administering the surveys;
- Presentation is everything if you want accurate data. Make people understand the purpose of the survey and that it is meaningful and for their benefit;
- Researchers training people on how to administer surveys may be beneficial;
- Sometimes the titles of surveys are really off-putting. A less-formal title could be used; and
- The survey facilitator should make it fun, simplify, and keep it short and to-the-point.

Appendix G: Consultants' recommendations about future workgroups

- More workgroup time should be dedicated to the RSA scale in particular because it is longer and more complex than the MARS scale;
- While the process of the workgroup was valued, consultants reported that more time is needed to fully appreciate it (i.e., 2 days instead of 1 ½, but no longer);
- The activity which asks consultants to select their top five most preferred items should allow more than five items to be selected on the RSA (e.g., top 10 should be selected);
- It is important to allow both time to look at questions alone and also to discuss as a group;
- The workgroup process should be broken up (i.e., go through the process once, then reconvene at a later date and do it again);
- Part of the workgroup process that emerged as valuable was peers educating researchers about the realities of their jobs;
- Consultants suggested being able to have administered the survey scales with one or two people as pre-work homework so they could offer more insight during discussion. Additionally, consultants could also gather feedback on individual items from people receiving services and bring those to the table;
- Ahead of future workgroups, researchers should observe some surveys being administered to directly observe the interpretation(s) being presented by survey administrators;
- Asking around the table more, so everyone has a chance to speak, would improve future workgroups;
- Consultants expressed interest in both Austin and San Antonio-based consultants coming back together as a combined group in order to get fresh perspectives without having to bring people up to speed;
- One consultant suggested that workgroup facilitators use more close-ended and specific questions to avoid lengthy discussions; and
- Consultants recommended inviting participants from a more diverse group of organizations and different working environments.

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