



INNOVATION AND  
VALUE INITIATIVE

## **MDD Advisory Group Meeting Meeting Summary**

December 14, 2020

### **Attendees:**

Gretchen Wartman, National Minority Quality Forum  
Nathaniel Counts, Mental Health America  
Susan dosReis, PAVE  
Karen Moseley, HERO  
Paul Fronstin, Employee Benefit Research Institute  
Benjamin Miller, Well Being Trust  
Mohannad Kusti, Optimal Workplace and Environmental Wellness Corporation  
Julia Slejko, PAVE  
Raquel Halfond, APA  
Susan Gurley, ADAA  
Jordana Schmier, Pharmerit  
Becky Yowell, APA  
Iman Nourhusein, Pharmerit  
Phyllis Foxworth, Depression and Bipolar Support Alliance  
Brian Gifford, Integrated Benefits Institute  
Sonya Snedecor, Pharmerit  
Cheryl Neslusan, Janssen Scientific Affairs  
Michael Grabner, HealthCore  
Rahul Dhanda, Neurocrine Biosciences, Inc.  
Debra Lerner, Tufts Medical Center  
Andrew Sperling, National Alliance on Mental Illness  
Kevin Ronneberg, Health Partners  
Jennifer Bright, IVI  
Erica deFur Malik, IVI  
Melanie Ridley, IVI  
Todd Bentsen, IVI  
Hanh Nguyen, IVI

The Major Depressive Disorder Advisory Group met for the fourth time on December 14, 2020. The purpose of the meeting was to review the initial findings from the qualitative stage of the Patient-Driven Priorities for the Management of Major Depressive Disorder Project. IVI and its research partners were seeking feedback from the Advisory Group on how to prioritize identified value elements.

## Key Takeaways from the MDD Advisory Group Meeting

MDD project has two parts:

1. Value Assessment model on major depressive disorder (Pharmerit)
2. Patient-Driven Priorities for the Management of Major Depressive Disorder (PAVE)

### Value Assessment Model Update

There was a brief update on the current value assessment model work. Currently they are:

- Completing initial literature review based on AG Feedback and surveys.
- Developing Initial Scoping Recommendations (to be presented at the January meeting).

### Patient-Driven Priorities for the Management of Major Depressive Disorder

The main purpose of the meeting on December 14 was to review initial findings from the interviews with 20 individuals living with major depression and to illicit initial feedback on which value elements were most important to prioritize for a discrete choice experiment survey.

### Demographic Background

There were 20 individuals who participated in 1 hour interviews with PAVE researchers, with a range of ages (more older adults), gender (more females than males), race (predominantly white), geographic region (all regions represented), and socio-economic status (all economic levels included).

- There was concern expressed about the lack of racial diversity in the interviews and whether the findings were valid across racial backgrounds.
  - Researchers and IVI acknowledged that while 1/3 of respondents were non-white, there is an ongoing challenging in recruiting diverse participants in research studies. This seems especially challenging when using small sample sizes because the numbers appear less representative than they are. The researchers are focusing on two issues to address this concern:
    - They see the next iteration and the survey as important opportunities to ensure diversity of responses.
    - They reviewed literature and found that these themes of access and affordability to be thematically representative across backgrounds.\*
    - Phyllis Foxworth DBSA reported that their research, including those of focus groups with specific minority groups, reflected these themes.
- Participants recommended writing the survey itself meet a fifth grade reading level to ensure accessibility.

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\* Dunlop, Dorothy D., et al. "Racial/ethnic differences in rates of depression among preretirement adults." *American journal of public health* 93.11 (2003): 1945-1952.

Richardson LP, DiGiuseppe D, Garrison M, Christakis DA. Depression in Medicaid-Covered Youth: Differences by Race and Ethnicity. *Arch Pediatr Adolesc Med.* 2003;157(10):984–989. doi:10.1001/archpedi.157.10.984

Citrome, Leslie, et al. "Prevalence, treatment patterns, and stay characteristics associated with hospitalizations for major depressive disorder." *Journal of affective disorders* 249 (2019): 378-384.

## Value Elements

There were five categories of Value Elements discussed:

- **Treatment Effects**
- **Life Impact**
- **Social Impact**
- **Affordability**
- **Access to Treatment**

Prior to the discussion, one of the AG members requested more background information about the methodology of the PAVE study and a clear explanation of how these fit into the value assessment model. *IVI and PAVE will send updated information to the MDD Advisory Group.*

Phyllis Foxworth (DBSA) shared background on some of the research DBSA has conducted on mood disorders, as it has relevancy to the project. They have conducted surveys and focus groups with hard-to-reach minority groups and found common themes to the ones identified by PAVE. A few insights from that research include:

- Since mood disorders are chronic disorders, symptoms don't matter as much. Individuals measure progress by what they are able to do in spite of their health condition.
- Some topics came up regardless of age. For example, ability to work/career would come up for people who were retired. "I didn't reach my full potential."

Nathaniel Counts (MHA) suggested that concepts of recovery might help in formatting the survey. MHA has found that social isolation has been a huge issue for their survey respondents, but had a huge boost due to the pandemic.

Phyllis Foxworth suggested that affordability "goes without saying." She encouraged researchers to explore the concept of provider relationship and trust. She pointed out that this connects to access to treatment, which then feeds into affordability.

Kevin Ronneberg suggested that many of the elements within the "affordability" category rolled up into the larger concept. What is needed to explore the nuances of affordability?

Several participants requested more explicit definitions of the elements. For example, how was "available treatment" defined?

Andrew Sperling (NAMI) spoke about how people go to extraordinary lengths to access treatments. He asked, "how does research capture that desperation for symptom relief, for a relief to that suffering?"

## Next Steps

- Share background information with AG Members
- Narrow value elements and explore how to capture nuances

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Chat Discussion

Jennifer Bright: So glad to see everyone here! As ever, please feel free to also chime in via the chat function to ensure we “hear” all of your great input and ideas!

Jennifer Bright: To ensure all know the acronym: DCE = discrete choice experiment, a research approach that helps to quantify how patients make tradeoffs among a range of value attributes. :)

rahul dhanda: adherence to medication?

Karen Moseley: I echo Gretchen's concern

Jennifer Bright: Gretchen, you raise an important point and one we are already thinking about v.v. a representative sample for the larger survey. Today’s question is whether our initial value element set appears to be valid from your experience and perspective AND ideas for how to ensure such representativeness as we proceed. Thanks for keeping us focused on priority 1!

Phyllis Foxworth: DBSA has a similar project. In our initial survey from 6,400 responses we had similar demographics. We corrected for that lack of diversity in focus groups. 4 groups with 31 participants including one group just for Hispanic males and one for Asian females. What we learned from our focus groups was a commonality around peer-identified preferred treatment outcomes regardless of race, ethnicity and race

Karen Moseley: Was there any analysis of responses to ensure that the elements of importance or top importance were fair representation across gender, race, education and residential community? Those were the areas that seemed to be less diverse in the sample.

Gretchen Wartman: My concern is if you fail to be inclusive at this stage, you bias the next stages of the study.

Phyllis Foxworth: We heard this from our PFDD meeting. Under employment was a leading theme from the attendees

Becky Yowell (APA): In talking thru this with Dr. Norquist who is unable to be here today), we had concerns that the reading level of the questions seemed higher than a 5th grade reading level and may skew the results.

Phyllis Foxworth: Your list is encouraging at our last stakeholder meeting in Nov. 19, the stakeholders identified the following concepts of interest:

Phyllis Foxworth: Improved physical energy

Phyllis Foxworth: Activities of daily living, time spent in positive vs negative space, maintaining/increasing relationships as desired

Cheryl Neslusan: While ability to work and impact on career are correlated, the extent to which is likely a function of disease severity. With such a small sample and skewed to the more severe (as evidenced by the number of people reporting brain stimulation) - ability to work might be more relevant here - However, for the more general MDD pop impact on career may be a concept that resonates more (allows for capture of working less than full potential). Perhaps should consider 2 exercises, 1 for those vs more severe vs less.

Brian Gifford: Another aspect of representation with regards to life impact: Ability to work rates as important, but 1 in 3 were retired or unemployed, and the same number listed their status as disabled. Getting more insights into what ability to work (e.g., function on the job vs labor force participation) means to respondents could be informative.

Cheryl Neslusan: As a LT chronic condition, Tx costs overtime reduce overall wealth- even if one can afford the Tx...

rahul dhanda: makes sense

Becky Yowell (APA): agreed - it is hard to tease those three out.

Becky Yowell (APA): Does "available" mean "covered by insurance"?

Jennifer Bright: thanks for the comments on affordability = very helpful

Debra Lerner: Could someone please distributed the PAVE methodology publication from 2020 or other relevant publications? I am still unclear how this information was elicited and classified. Thank you.

Jennifer Bright: Deb and all. We will certainly share again the methodology and also the earlier shared documents that began this conversation. :)

Debra Lerner: I checked the slides but would love to see more. Thanks very much!