



# SUPPORTING WELLNESS

A Survey for Depression and Bipolar

## Supporting Wellness Results

April 2019



SUPPORTING WELLNESS

A survey of lived experience and research priorities for depression and bipolar

## Raising Voice of Peers

**1<sup>st</sup>** survey of  
its kind

6,405 responses

Patient driven research



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## 18 multiple choice and open response questions

Demographics, defining wellness/research priorities



## Self-identified as:

- Living with depression or bipolar or symptoms of these conditions
- In a relationship with someone who lives with depression or bipolar



**12-minute**  
average completion time



## Informed by the Lived Experience

### Partners

DBSA: Leading peer-directed organization for people living with mood disorders

Milken Institute Center for Strategic Philanthropy

### Advisory Committee

Mental Health America · The Starr Coalition  
· Massachusetts General Hospital · Omega Recovery · Kith Collective · The George Washington University · PCOS Challenge

### Peer Review

8 peers provided over 180 minutes of feedback

- Launched in August 2018
- Promoted through DBSA chapters, newsletters, Facebook
- Milken Institute: press release, social media
- Program partners
- 23 and Me



## Consistent with Other Surveys

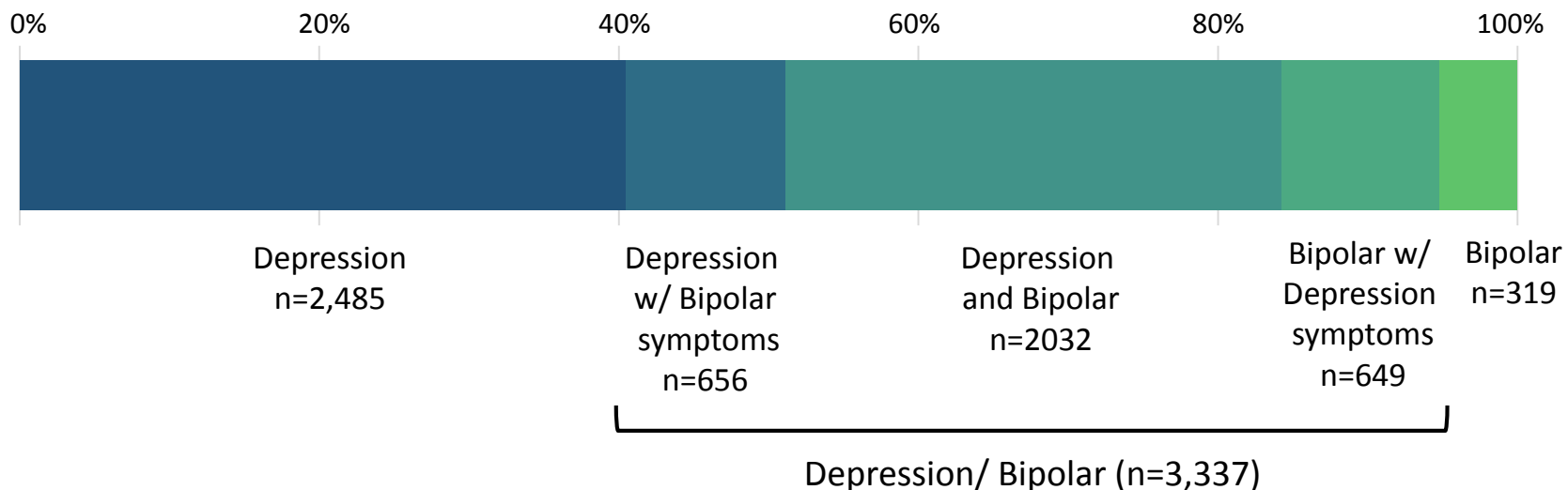
|                               | Combined<br>(n=6,405) | Community<br>Engagement (n=3,920) | 23andMe<br>(n=2,485) |
|-------------------------------|-----------------------|-----------------------------------|----------------------|
| <b>Sex</b>                    |                       |                                   |                      |
| <i>Female</i>                 | 5096 (80%)            | 3054 (78%)                        | 2042 (82%)           |
| <i>Male</i>                   | 1100 (17%)            | 767 (20%)                         | 333 (13%)            |
| <b>Age</b>                    |                       |                                   |                      |
| <i>18-34</i>                  | 2373 (37%)            | 1049 (27%)                        | 1324 (53%)           |
| <i>35-54</i>                  | 2794 (44%)            | 1638 (42%)                        | 1156 (47%)           |
| <i>&gt;54</i>                 | 1211 (19%)            | 1209 (31%)                        | 2 (0%)               |
| <b>Race/ethnicity</b>         |                       |                                   |                      |
| <i>White</i>                  | 5411 (85%)            | 3239 (83%)                        | 2172 (87%)           |
| <i>Asian/Pacific Islander</i> | 140 (2%)              | 100 (3%)                          | 40 (2%)              |
| <i>Black</i>                  | 210 (3%)              | 167 (4%)                          | 43 (2%)              |
| <i>Hispanic</i>               | 266 (4%)              | 175 (4%)                          | 91 (4%)              |
| <i>Native American</i>        | 44 (1%)               | 30 (1%)                           | 14 (1%)              |
| <i>Other</i>                  | 310 (5%)              | 187 (5%)                          | 123 (5%)             |
| <i>(Non-white)</i>            | 970 (15%)             | 659 (17%)                         | 311 (14%)            |



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# Majority Live with Depression and Bipolar





## Segments: Age, Gender, Orientation, Race

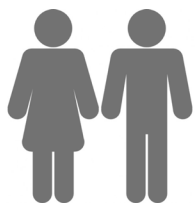
|                           | Depression<br>(n=2,485) | Bipolar (n=319) | Depression/Bipolar<br>(n=3,337) | Total<br>(6141) |
|---------------------------|-------------------------|-----------------|---------------------------------|-----------------|
| <b>Age</b>                |                         |                 |                                 |                 |
| 18-34                     | 1002 (40%)              | 78 (24%)        | 1257 (38%)                      | 2337 (38%)      |
| 35-54                     | 1033 (41%)              | 158 (50%)       | 1504 (45%)                      | 2695 (44%)      |
| 55+                       | 443 (18%)               | 81 (25%)        | 669 (20%)                       | 1093 (18%)      |
| <b>Gender</b>             |                         |                 |                                 |                 |
| Male                      | 392 (16%)               | 65 (20%)        | 586 (18%)                       | 1043 (17%)      |
| Female                    | 2007 (81%)              | 249 (78%)       | 2648 (79%)                      | 4904 (80%)      |
| Non-binary                | 71 (3%)                 | 1 (0%)          | 84 (3%)                         | 156 (3%)        |
| <b>Sexual Orientation</b> |                         |                 |                                 |                 |
| Heterosexual              | 1866 (75%)              | 258 (81%)       | 2329 (70%)                      | 4453 (73%)      |
| Gay or lesbian            | 126 (5%)                | 15 (5%)         | 209 (6%)                        | 350 (6%)        |
| Bisexual                  | 339 (14%)               | 35 (11%)        | 602 (18%)                       | 976 (16%)       |
| <b>Race/Ethnicity</b>     |                         |                 |                                 |                 |
| White                     | 2142 (86)               | 266 (83%)       | 2790 (84%)                      | 5198 (85%)      |
| Non-white                 | 338 (14%)               | 51 (16%)        | 541 (16%)                       | 930 (15%)       |



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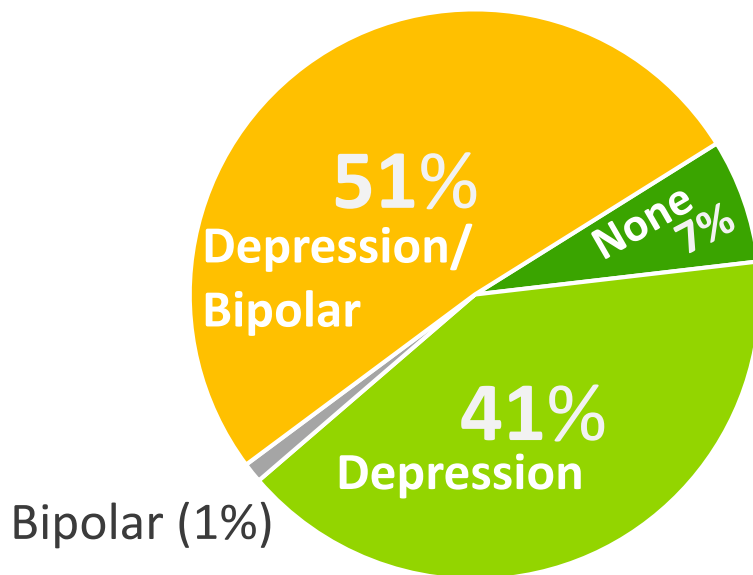
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# 92% Caregivers Also Experience Mood Disorders



# 41%

Of respondents indicated that they were caregivers



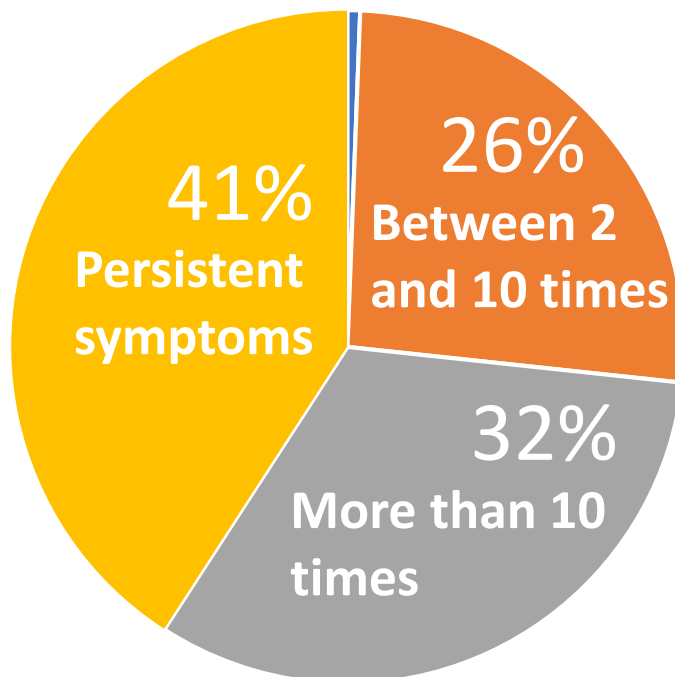


# Key Observations



## Time Spent Living with Symptoms

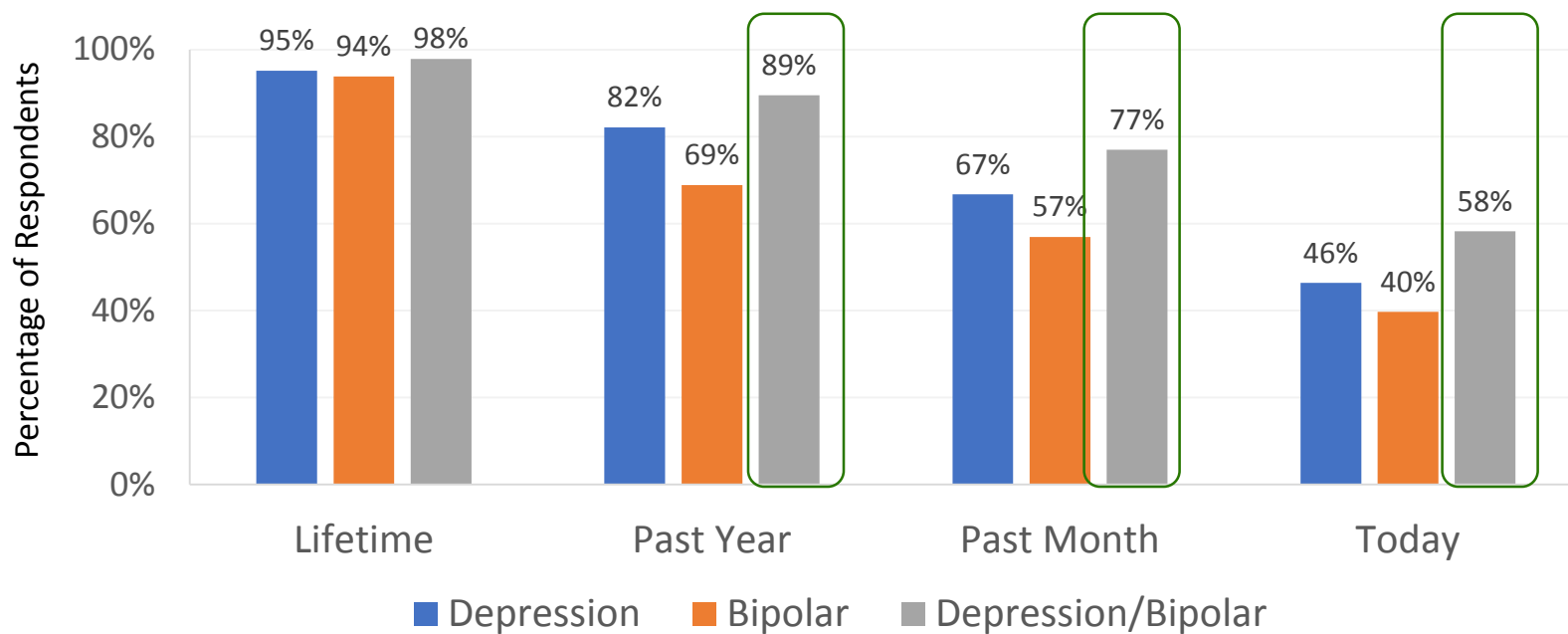
73% experience 10 or more discrete periods or persistent symptoms throughout their life.





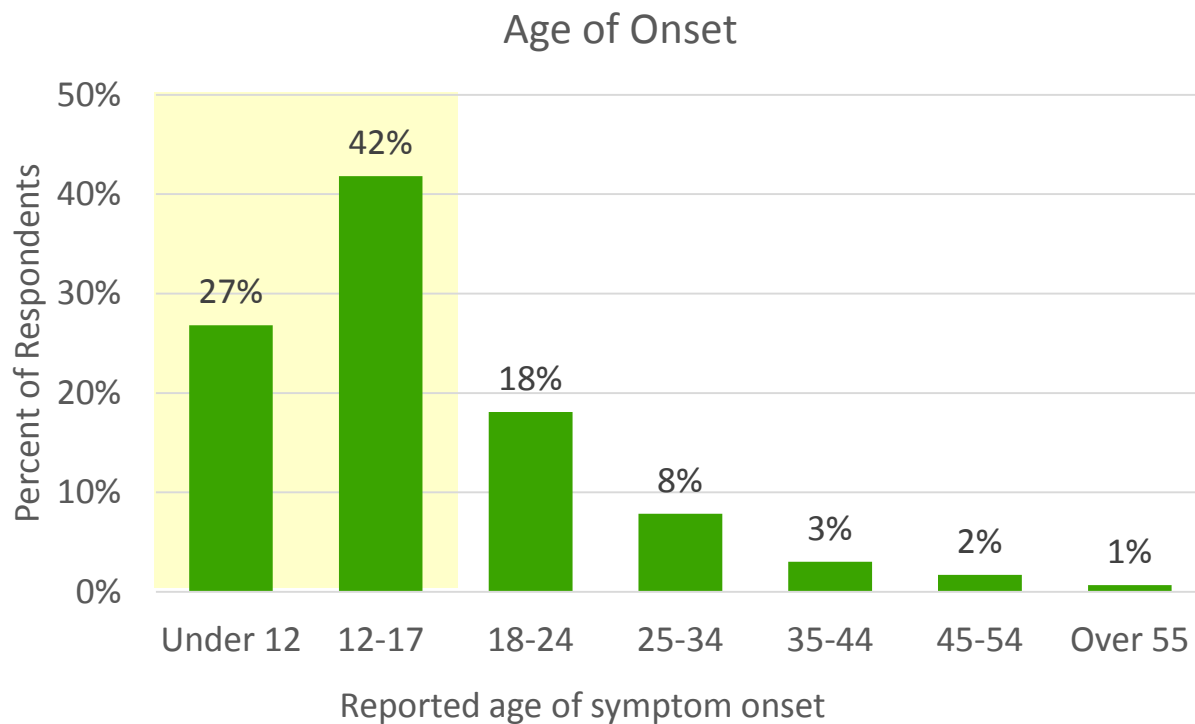
## Acute Impact Greatest Among Self-Defined Group

Underscores need for peer-desired and defined outcomes.



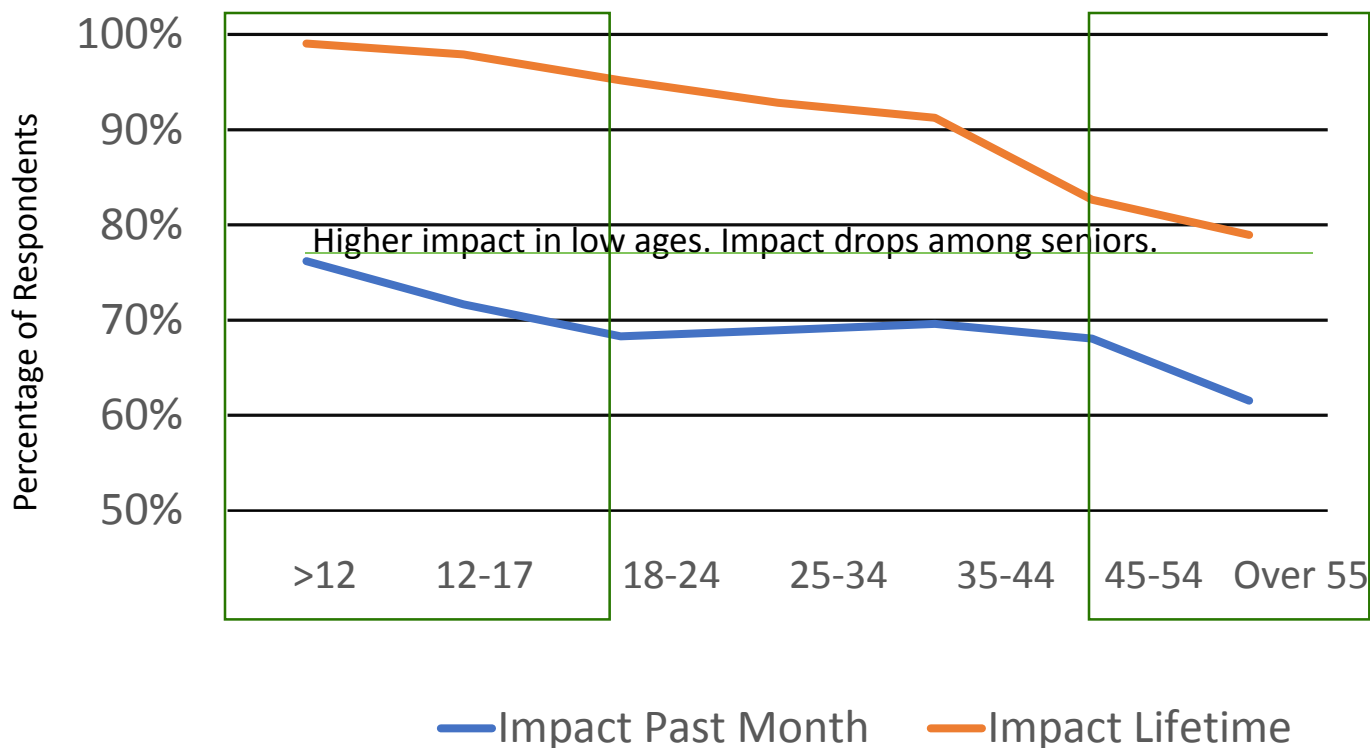


## 69% Experienced Symptoms Before Age 17





## Age of Onset Affects Perceived Lifetime Impact





## Peer-Desired Health Benefit vs Reality

Are peers getting what they want from treatment?

### STRONGLY AGREE or AGREE

**91%** Goal in health is to **function** as well as possible

**83%** I think in terms of how well I **function** at work, play and connect with others

**Personal  
Definition  
of Health**

**Personal  
Reflection on  
Healthcare  
Environment**

### STRONGLY AGREE or AGREE

**89%** There should be better ways to treat and provide care

**66%** My healthcare team is strongly focused on **symptoms**

**43%** Are not satisfied with care



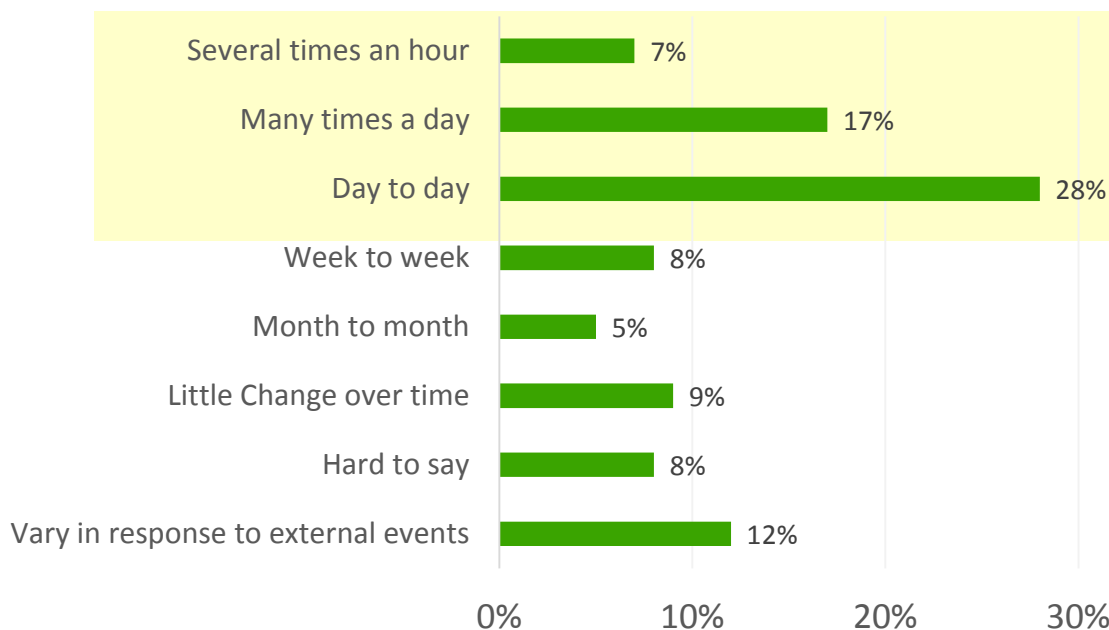
# How Peers Experience Mood Disorders



## Aspects of Wellness Fluctuate

More than half predict aspects might change one or more times within 24 hours.

### How often self-defined aspects of wellness change





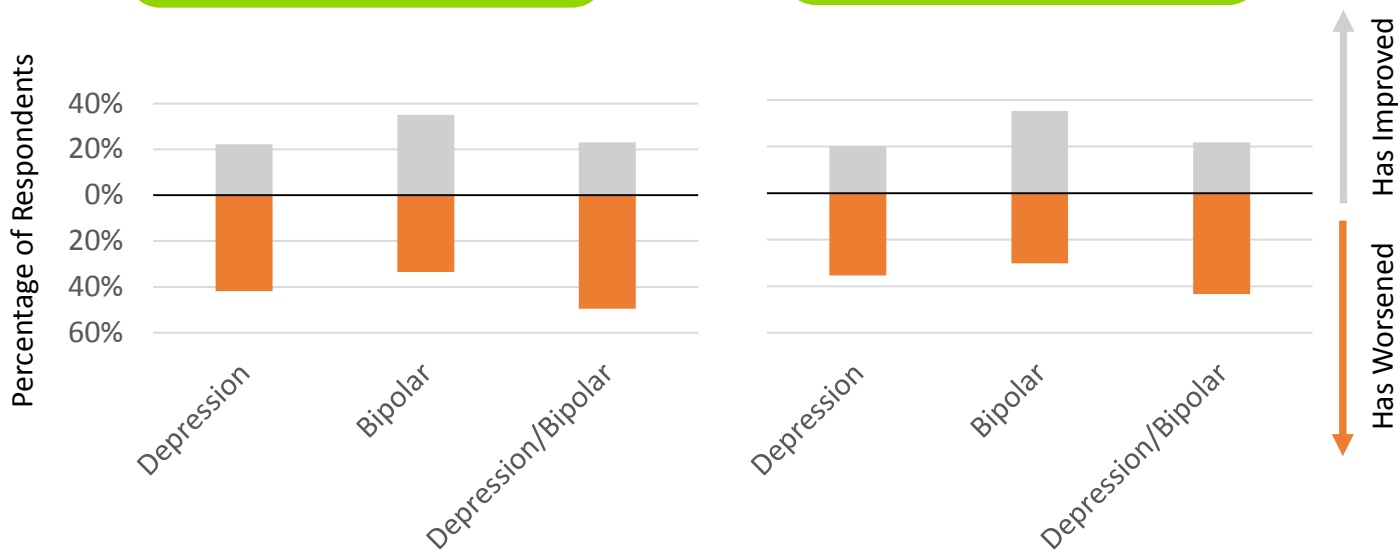
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## Condition Impacts Whole Health

44% overall  
health worse

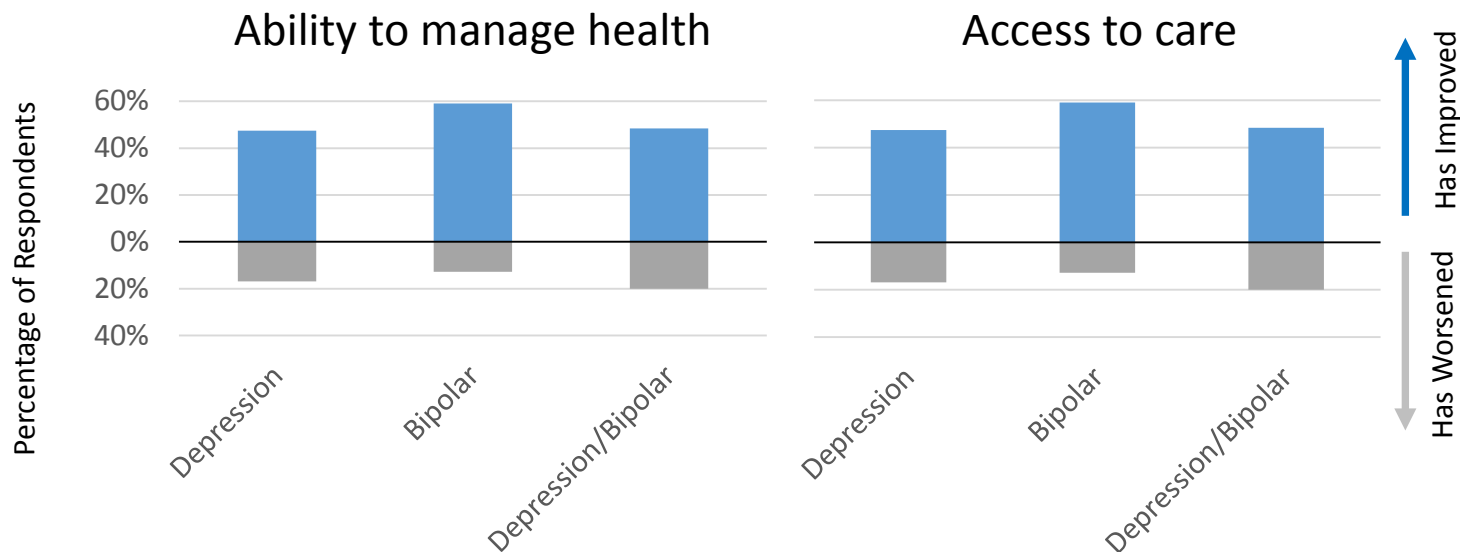
38% stability of  
health worse





## Access to Care Provides Hope

Ability to manage health and access to care improves across all groups.





# How Peers Define Wellness



## Peer-Desired Outcomes Extend Beyond Symptoms

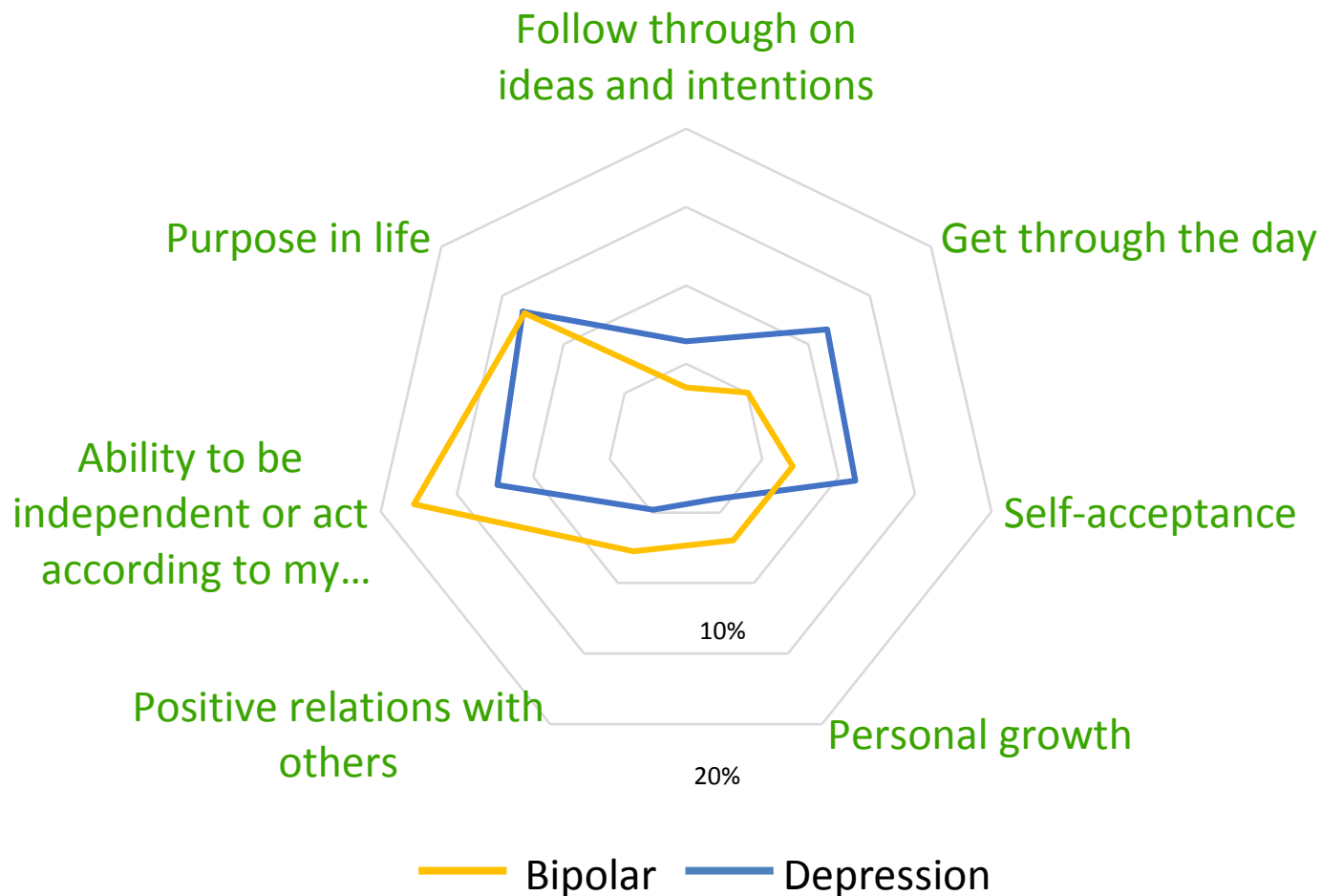
| Rank | % Stating Aspect is "High Priority" | Priority                                                  |
|------|-------------------------------------|-----------------------------------------------------------|
| 1    | 86%                                 | Ability to be independent or act according to my own will |
| 2    | 74%                                 | Purpose in life                                           |
| 3    | 81%                                 | Get through the day                                       |
| 4    | 73%                                 | Self-acceptance                                           |
| 5    | 63%                                 | Calm and relaxed presence                                 |
| 6    | 63%                                 | Follow through on ideas and intentions                    |
| 7    | 75%                                 | A sense of influence over the events in my life           |
| 8    | 65%                                 | Recover quickly from difficulties                         |
| 9    | 71%                                 | Positive relations with others                            |
| 10   | 68%                                 | Personal growth                                           |



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# Place Along Spectrum Affects Wellness Priorities



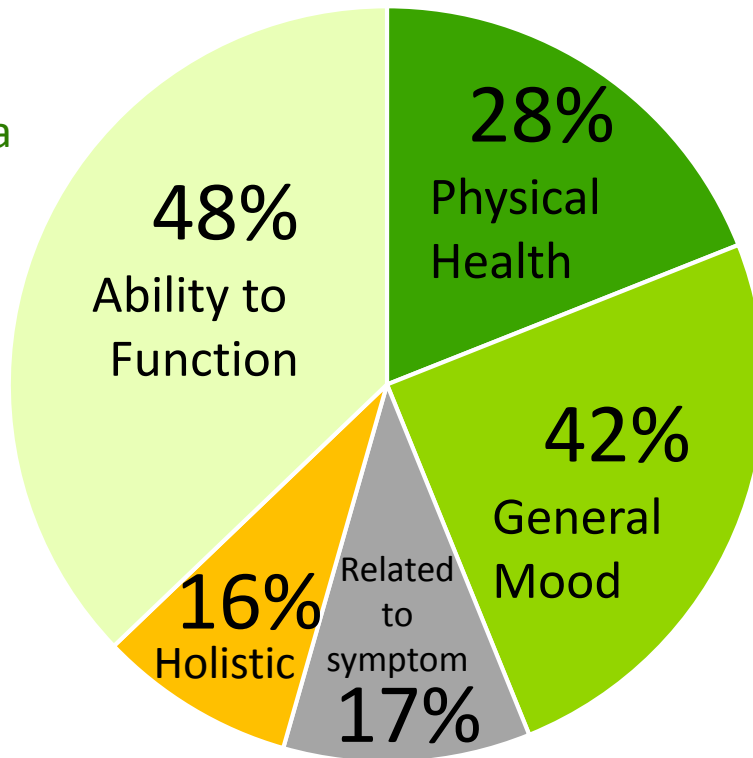


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# What's Most Important to Peers

"It means stability;  
well enough to hold a  
job, well enough to  
enjoy activities, well  
enough to feel joy  
and hope."



It's all parts of me; my  
mind, body, and spirit.

"To feel joy again."

"Not having bipolar episodes."



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## Quality of Life / Ability to Function

Described in terms of sense of control

### “Quality of Life” Drivers



### “General Mood” Drivers





## Mood

Most common: contentment/acceptance

| Category                      | N (% Total)     |
|-------------------------------|-----------------|
| General                       | 174 (4%)        |
| Absence of Negative Mood      | 179 (4%)        |
| <b>Contentment/Acceptance</b> | <b>418 (9%)</b> |
| Positive Outlook              | 101 (2%)        |
| Stability                     | 210 (4%)        |
| Feeling Normal                | 79 (2%)         |

“To be content and happy with life and everyday living.”



## Physical Health

Overall general health is most important

| Category                 | N (% Total) |
|--------------------------|-------------|
| General                  | 385 (8%)    |
| Other                    | 116 (2%)    |
| Self-care                | 88 (2%)     |
| Fitness/Active Lifestyle | 85 (2%)     |
| Diet                     | 73 (2%)     |
| Sleep                    | 70 (1%)     |
| Energy                   | 69 (1%)     |

“Body weight within normal range, emotionally healthy and able to function at school, work and in public. “



# Peer Identified Research Priorities

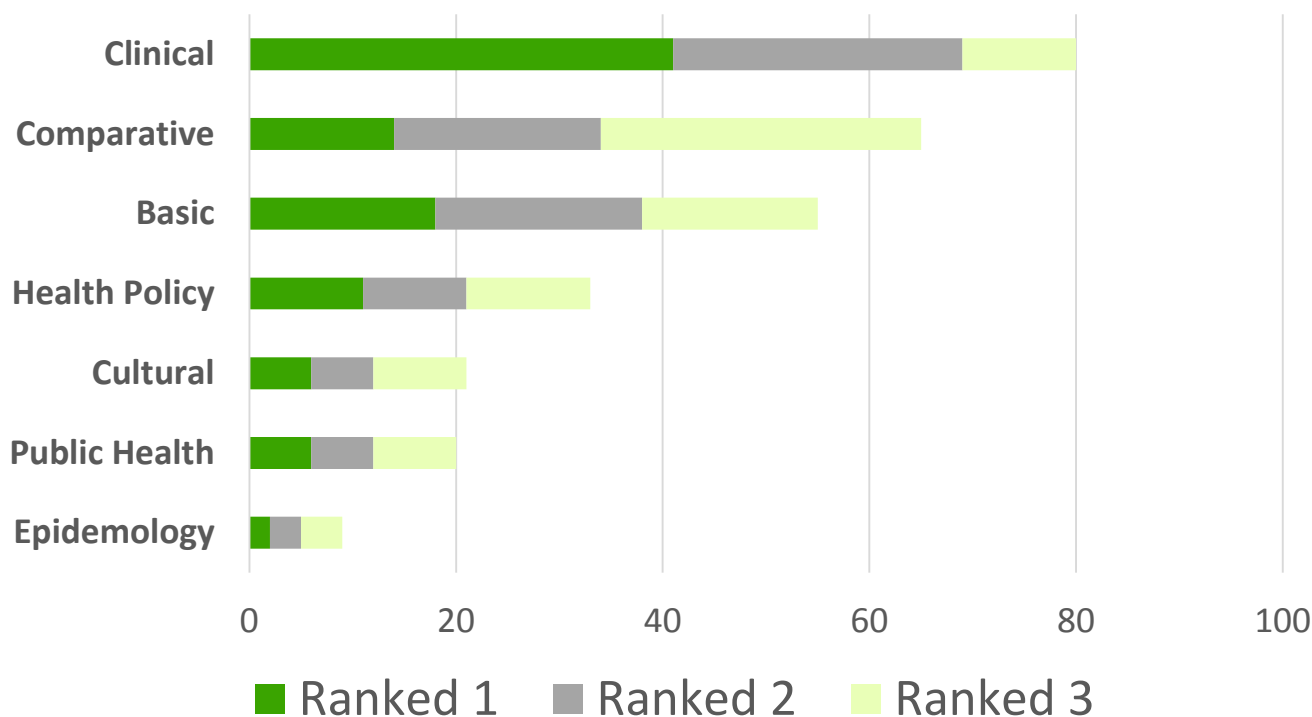


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# Peers Prioritize Clinical Studies

Top research priorities by “rank”





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> 90% want better treatment strategies and over 80% would be willing to take action to accomplish that goal.

“I believe there should be better ways to treat and provide care for people with depression and/or bipolar”



“I am willing to take action to help improve the state of treatment and care for people with depression and/or bipolar”



Strongly Agree   Agree   Neutral   Disagree/ Strongly Disagree



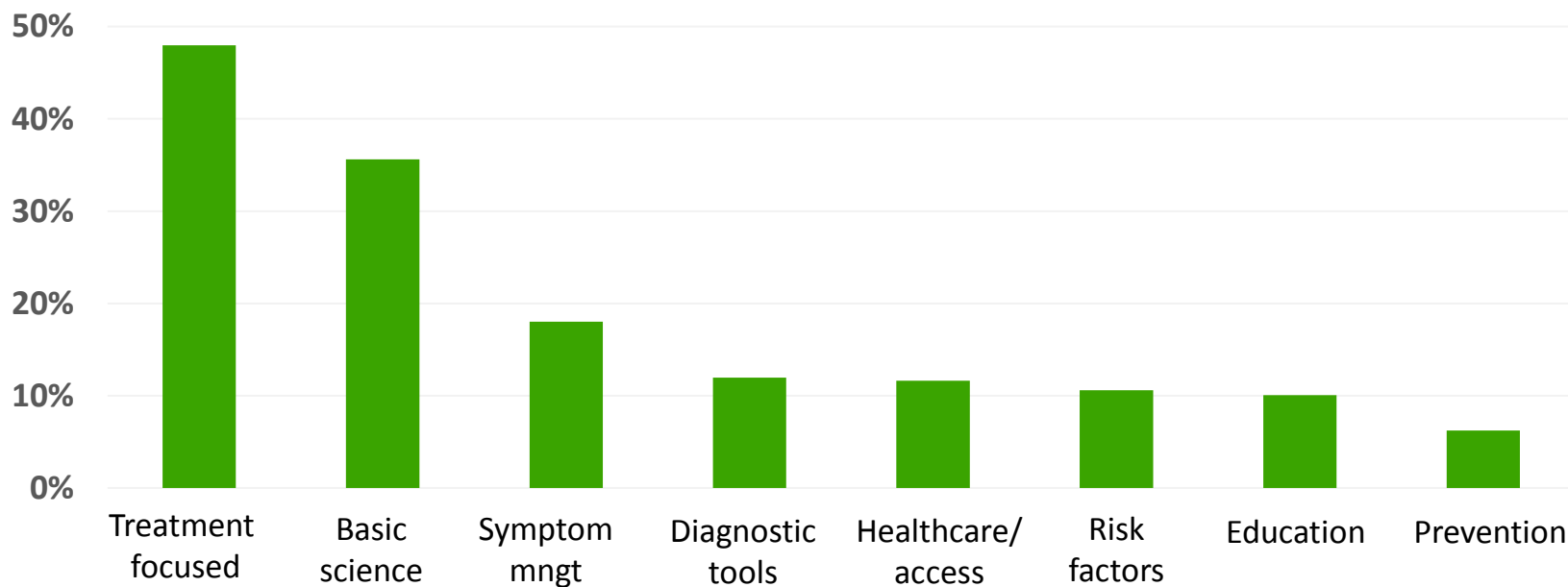
Open-ended responses highlight specific research priorities specifically the identification of new treatments and greater understanding of the conditions.

| Category                        | Quote                                                                                                                                                                                                                                                                                                               |
|---------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Treatment                       | How to get the best balance between efficacy and side effects with medication.                                                                                                                                                                                                                                      |
| Treatment                       | Mood stabilizers are great except for what it does to your blood sugar levels. When you have a history of diabetes, this is a double edged sword leading to tough decisions.                                                                                                                                        |
| Treatment                       | A longer acting medication or implantable device for depression/Bipolar? 1 missed dose causes several days of problems and trouble for the entire family.                                                                                                                                                           |
| Treatment                       | How to identify the best treatment for a particular patient.                                                                                                                                                                                                                                                        |
| Basic Science                   | I would like more research into the causation of the disease related to social and/or cultural events in someone's life. Also, better research on the effects of medication on the physical health of an individual.                                                                                                |
| Basic Science                   | Information about how genes and brain activity/differences cause/influence bipolarity and the experience of depression. How does my brain function differently than normal people's brains? What chemicals/ regions/reactions are part of that? How do these impact the way I process information, feel and behave? |
| Basic Science/ Diagnostic Tools | What is the biological cause of depression? How can we test for the physiological presence of depression?                                                                                                                                                                                                           |
| Symptom management              | What behaviors have I engaged in to help alleviate or mitigate in the symptoms of my bipolar disorder                                                                                                                                                                                                               |
| Diagnostic Tools                | I would just have liked to have had an easier time diagnosing my condition                                                                                                                                                                                                                                          |
| Diagnostic Tools                | A way for an accurate diagnosis to my or anyone's mental health issue. Right now, it's always "it could be this, or possibly that, or maybe a combination.                                                                                                                                                          |
| Risk factors                    | How do I prevent my son from inheriting it?                                                                                                                                                                                                                                                                         |



## Research Priorities

Open-ended responses highlight the need for new treatments and better basic understanding of disease.





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To learn more

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