

Borderline Personality Disorder Advocacy Guide
for NIMH's Request for Information on the State of Mental Health Research
Deadline to Complete: June 30, 2016

The National Institute for Mental Health (NIMH) is interested in what you think the research agenda for borderline personality disorder (BPD) should be. It allows you to write up to 500 words about what matters TO YOU. We ask you to describe the NEED that YOU SEE as someone who has been impacted by BPD.

In order to get to that goal, follow the steps below. These steps may seem a little tedious, but they lead to the main event: communicating your thoughts about what is needed in BPD research!

Step 1 – Think about what you want to tell NIMH about the need for more BPD research (You probably agree with all of these; pick the one(s) which are most important to you.)

There are many reasons why more borderline personality research is needed. Here are a few common responses based on data from Emotions Matters recent petition on Change.org:

- **Stigma from health care professionals** who are afraid to treat people with BPD because of their inadequate training on personality disorders.
- **Lack of general public awareness of BPD** which negatively impacts how people in society view those with BPD, especially those in public institutions like schools, hospitals or law enforcement agencies that interface with the BPD population.
- **Helping individuals with BPD understand their disorder** and what is going on in their brain. Research can help with psychoeducation, self-help, and community support.
- **High rate of suicide** associated with BPD, affecting 10% of those diagnosed.
- **Poor daily functioning** associated with individuals with BPD who are on disability, unemployed, homeless, don't finish school, and lack stable social relationships.
- **Devastating emotional pain** experienced by those who live with BPD on a daily basis.
- **Devastating impact of BPD on families**, children, partner and society.
- **The need for early intervention and prevention**, as many with BPD claim it emerged during the adolescence, when more support and intervention was needed.
- **Discrimination from insurance companies** who do not recognize BPD as a legitimate mental health disorder which deserves coverage on parity to other mental illness.
- **The high rates of misdiagnosis** illustrates the lack of general understanding of how to properly identify, classify and treat those with BPD.
- **The relative in accessibility and high cost of BPD treatment.** The vast majority of those who have BPD cannot afford the expenses associated with BPD interventions while treatment can be highly cost effective over time.
- **Having a better understanding of BPD and the role of medications.** Many with BPD express concerns about being overmedicated, others are helped by medicines, while others do better without medicines, but we have little knowledge about why.
- **Helping doctors select the best interventions for the BPD individual.** There are many different therapies to treat BPD (dialectical behavioral therapy, mentalization, transference focused therapy, mindfulness, good psychiatric management), that some respond to, while others do not. We need more knowledge to optimize matching patient presentation with the treatment modality that will be most effective for recovery, as treatments are costly and time-intensive.

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Step 2 – Write a response on your SPECIFIC CONCERN in 500 words or less.

This is the FUN part you have been waiting for....the chance to share your experience/opinions on the need for borderline personality disorder research to the highest government institution for mental health research in the United States!

Here are some writing tips:

- If you have a personal connection to BPD, share it! Personal stories speak volumes!
- Include some identifying information about yourself (age, where you live, individual to BPD, family member, cultural/ethnic background, gender, etc.)
- Give specific examples to illustrate why the particular topic you are advocating for is important to you and necessary to meet the public health needs of the BPD population.
- Explain how having more of this particular type of research might change/or have changed the treatment outcome in your specific situation.
- Offer real-world insight and or explanations to explain the impact of BPD on you, your family or your community.

Example#1: (from perspective of individual with BPD)

- My name is Mary Smith. I am 22 years old and am writing from Atlanta, Georgia. I am writing because I think more research is needed to understand borderline personality disorder so doctors can know what it is, and treat it properly. I was first diagnosed with borderline personality disorder when I was 19 after many misdiagnoses and doctors.

I can't remember a time when I didn't have anxiety and emotional problems. They first said that I was bi-polar and had depression. Since I was 13 years old, doctor after doctor put me on so much medicine, like anti-depressants and anti-anxiety medicines. But nothing really changed, and my body got all screwed up from the meds. After two suicide attempts and hospitalizations my psychiatrist suggested it was borderline personality disorder.

I had never heard of BPD before. The doctor said it was a difficult diagnosis and I was scared, like I would never get better. When I read on the computer about BPD, it said people with this disorder are manipulative and violent. I felt like a freak and was very ashamed. It took a while for me to find a therapist who could even treat BPD and explain it to me so I had hope for the living. More research on the neurobiology of BPD will help inform doctors about BPD, and make it more hopeful, accepted diagnosis.

When I learned about more BPD, it totally made sense. I struggle with my emotions and behaviors, have difficulty with friendships. My moods change rapidly and I am chronically feeling empty and invalidated. The emotional pain is excruciating.

It makes me so angry that doctors put me on so much medication as young as 13, when what I really needed all along was intensive therapy. I feel like I lost years of my life when I was on those medications and misdiagnosed. Now I have dialectical behavioral therapy, and it has helped me control my moods. I have made progress, but every day is still a struggle. I am always scared my doctor will leave me, and then I will have to find someone new. There are so few doctors in Atlanta who treat BPD.

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More research from the National Institute of Mental Health is important to help doctors' diagnosis people properly and get them off medicine and into treatment faster. It will make those who suffer every day with BPD like me to understand what is going on in their brain. This fits perfectly with NIMH's strategic objective to define the mechanisms of complex behaviors. More brain research is needed to increase awareness for both those with BPD, for doctors, and the general public.

More brain Research on BPD will validate what we have as a real illness, and not just some character flaw. Research will give me and the thousands of others out there struggling to survive hope for better treatment and support in the future.

(Category#1 Basic Neuroscience Research; Strategic Objective #1: Define mechanisms of complex behaviors).

Example #2: (from perspective of family members)

My name is John Jackson. I live Montclair, New Jersey, and my 32 year old daughter Betty has borderline personality disorder. Although she has had mental health issues since she was a child, she was only recently diagnosed with BPD after a suicide attempt. Seeing her try to take her life was the worst thing I have ever experienced, and I would do anything to help her.

Worrying about Betty has been my number one priority, but it is a 24 hour marathon to help her regulate her emotions, stop her from self-harm or impulsive behaviors. I have gone to bed at night, sometimes not knowing where my daughter is, and if she is safe. We have found her on the street, taking drugs, with strangers, and in unsafe situations. It is frightening and we feel like we are constantly walking on eggshells, praying she is alive and safe.

I am writing to advocate for more services research about borderline personality disorder. Since Betty was diagnosed, it has been very difficult to get her into treatment. Although there are therapists who treat BPD in our area, the majority are private pay out of my health insurance network, and we cannot afford it.

I have called the health insurance company many times to explain that she needs therapy like TFP or DBT -- that she will die without it. They said that it is not a billable diagnosis. They say to take her to the emergency room if we fear for her safety. We have taken her to the emergency room six times in the past four months, and it is a revolving door with no end in sight. So Betty is not currently in treatment because we can't afford it. And because it's not covered, she says she doesn't need it.

More research on the discrimination that those with BPD experience from health insurance companies who refuse to cover treatment is necessary to keep my daughter alive. I have already spent a significant amount of my savings for her to see doctors and have evaluations. Why is depression and bipolar disorder covered by insurance and BPD is not? It does not make sense to me how an illness as devastating as BPD is not recognized as a legitimate mental illness covered by health insurance companies. I live in the United States of America and my daughter is mentally ill. Does she not have the same right to live – to receive treatment – as others with mental illnesses?

Services research will demonstrate discrimination and the need for structural changes in mental health benefits for those with BPD. This fits with the NIMH's strategic objective to strengthen the public health impact of research. This could literally save Betty, and keep my family out of debt. Thank you.

(Category 5: Services Research; Strategic Objective #3: Strengthen the Public Health Impact of NIMH Supported Research).

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Step 3 – Connect YOUR CONCERN with a specific NIMH topic listed in RFI Survey.

The NIMH is asking for feedback on specific categories related to the current state of mental health research. Category selections are subjective, and the opinion of the writer. Here are simple definitions to help you choose a submission category.

1. **Basic Neuroscience research** – This is aimed at understanding the underlying structure of the central nervous system and brain function (in utero, human or animal models).
2. **Translational research** – This translates basic science to discover the trajectory of mental illnesses, how they develop in a human or animal model over time, with a focus on developing new interventions and prevention.
3. **Clinical Research** – This involves human studies involving a person or group of persons studying their behavior or samples of their tissues.
4. **Intervention Research** – This studying the effectiveness of interventions or treatments and their impact on those who those are impacted by mental illness.
5. **Sservices Research** – This studies how social factors, financing systems, organizational structures, health technologies, and behaviors affect access to mental health care.
6. **Research Domain Criteria Initiative (RDOC)** - RDoC is a research framework for new ways of studying mental disorders, integrating many levels of information (from genomics to self-report) to better understand basic dimensions of functioning underlying the full range of human behavior from normal to abnormal.
7. **Global Mental Health** – This studies scientific innovation around the globe to transform the understanding of mental illnesses; provide tangible benefits for people with mental illnesses (e.g., symptom relief, improved functioning, better quality of life); and, lead the way to prevention, recovery, and cure. Mental disorders contribute a substantial proportion of the global burden of disease.
8. **Translational Biomarkers** – This area of research involves translating lab findings into the design and implementation of early-stage clinical trials. TM focuses on translating pre-clinical data from in vivo or in vitro research into clinical trials for new medicines. .
9. **Diversity and training of workforce** – This area of research enhances the diversity of the workforce by providing support to students, post-doctorates, and eligible investigators from underrepresented groups in health-related research.
10. **Advocacy and outreach efforts** – This category offers feedback on how NIMH interacts with advocates for individuals with mental illness, as well as professional, scientific and community-based organizations interested in the mission and/or programs of NIMH.
11. **The Institute's intramural research efforts** – This category offers feedback on how conducts basic, clinical, and translational research at its own labs to advance the understanding of the diagnosis, causes, treatment, and prevention of mental disorders.

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Step 4 – Connect your issue and topic with one of NIMH's strategic objectives.

The NIMH has four strategic objectives for the next five years:

1. Define the mechanisms of complex behaviors.
2. Chart mental illness trajectories to determine when, where, and how to intervene.
3. Strive for prevention and cures.
4. Strengthen the public health impact of NIMH-supported research

In your response, explain how your topic advocating for BPD research meets one of these strategic objectives. Keep in mind that selecting topics and a strategic objective for each is entirely subjective and based on the opinion of the writer.

Step 5 – Click the “Submit” Button!

Thank you! Every submission will help raise awareness about the importance of BPD research at the National Institute of Mental Health (NIMH).

DUE DATE: ALL SUBMISSIONS MUST BE SUBMITTED ELECTRONICALLY BY JUNE 30, 2016 via web link: <https://nimhrfi.nimh.nih.gov/portal/>.