

Janssen + Bakamo

Understanding the online patient voice 2017-18

Some people suffering from depression post on social media, saying what comes to mind about their condition. Those who want to better understand how to help can listen to these authentic accounts, without biasing real people's stories with the influences of focus group settings or question phrasing. By observing rather than asking, we also avoid intensifying suffering and creating new dangers among those suffering depression.

In 2017, pharmaceutical company Janssen asked Bakamo to conduct such a social listening study. Janssen wanted to use this insight to make choices about the best ways to communicate the benefits of antidepressant nasal spray Esketamine to Health Care Providers (HCPs) and patients in five European markets.

At Bakamo, we designed an approach to harvest the relevant mentions of *major depressive disorder* (MDD) as the overall topic, with two sub-categories: *treatment-resistant depression* (TRD), and *major depression with suicidal ideation* (MDSI). Using Bakamo's listening technologies and expert human judgement, we filtered to a group of authentic voices which we felt best represented the tone and content of comments in the relevant five European markets made over the preceding 12 months, determining geographical locations through a combination of geotagging, IP address analysis, language, and the judgement of native-speaking analysts on colloquialism.

From the resulting 7 million comments, we sought deep insights on dominant topics, perceptions, and emotions, beginning with the words sufferers used. Their language revolved around the imagery of *blackness* and *emptiness*: in Italy, some said *black beast* (*bestia nera*); in Spain *sea* (*mer*); in France *emptiness* (*vide*); in the UK *black cloud*; and in Germany *the black dog* (*schwarzer hund*).

We then selected 5,000 comments, 1,000 in each market, and our team of native-speaking analysts interpreted the depth and detail of the broader social and cultural context. Before our study, other research had presumed that comments on depression that expressed shame, belittlement, or ridicule might not be relevant to the research, but we observed that these expressions of emotional pain were often identifiers of shared experiences and the foundations of spontaneous online communities that provided validation, advice, and encouragement to sufferers.

We went on to apply a refined search syntax, gathering a further half a million relevant comments from discussions among those caring for people suffering depression, 500 of which from each market our experienced human analysts coded to define numerically the size and shape of the dialogues. We discovered that while conversations among carers accounted for

only a small fragment of the wider depression discussion, they offered powerful guidance on carers' vital roles in diagnosis and in advice on treatment.

Finally, we revealed how sufferers' experiences fluctuated over time and tended to be cyclical. As feelings of hopelessness were intensified by clinical factors or life events, sufferers sank deeper into depression, pushing them further into vulnerability. For many, as time passed and new treatments failed and they relapsed, sufferers became more hopeless, finding it hard to distinguish themselves from their condition.

For TRD sufferers, their experiences were dominated by frustration at the lack of effective treatments and only those who believed their condition to be external to them still wished to find effective drugs. Other patients learned to reject entirely the potential of pharmacological treatment with alternative solutions becoming the only way out.

For MDSI sufferers, as their journeys progressed, many increasingly internalised their conditions and became more resigned, losing all faith in treatment. The more hopeless many MDSI patients felt, the more uncontrollable and chaotic their lives seemed, and the greater the risk of them deciding to end their lives became.

By capturing the entire depression online conversation, and revealing these experiences and needs, our study empowered Janssen to better understand the journeys of those most in need and how they could be reached and helped by using resonant language and targeted communications.

Please contact [James MacGregor](#), Managing Director at Bakamo Public, for more information.