

**GAMIAN-Europe**  
**Pan European Stigma Study (2006-2010)**

**MEP Interest Group on Mental Health, Well being and Brain Disorders**  
**Meeting of 3<sup>rd</sup> May 2011**

Gamian-Europe has set up a first survey in 2006. The results were recently published in the Schizophrenia Research

*(Brohan, E., et al., Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe ..., Schizophr. Res. (2010), doi:10.1016/j.schres.2010.02.1065)*  
and in the Journal of Affective disorders

*(Brohan, E., et al., Self-stigma, empowerment and perceived discrimination among people with bipolar disorder or depression in 13 European countries: The GAMIAN–Europe..., J. Affect. Disord. (2010), doi:10.1016/j.jad.2010.09.001)*

In 2010, a second survey was set up. *(with financial support of Lundbeck International Neuroscience Foundation)*

Identical questionnaire in 20 languages, involvement of patient-associations in 23 European countries. Period for responding: end July end December 2010.

This survey is specific:

- User-run initiative: Self reporting, supported by the local national patient association.
- Accessible to all patients:
  - o No language barrier: everyone can respond in his or her own language
  - o Both online and printed version, accessible at the GAMIAN website (more than 7.000 visits of the questionnaire-page)

Research on self stigma or internalised stigma is important:

- Provides a solid foundation for stigma researchers
- Helps policy makers to understand outcomes of actions
- Helps clinicians to know the extent to which internalised stigma adversely influences therapeutic outcomes
- Defines target populations for future health promotion strategies

Importance of longitudinal research:

- Building a stronger longitudinal research would improve the potential for identifying people who are at risk for developing a high level of internalized stigma  
*(Livingston & Boyd, Social Science & Medicine, 2010)*

Aims of the project:

1. To measure the levels of stigma that people with a mental illness feel towards themselves, across Europe (**Internalised stigma**);
2. To measure the degree to which people with a mental illness believe that the general public hold negative attitudes towards the mentally ill (**Perceived devaluation/discrimination**);
3. To measure the levels of self-esteem and feelings of power/control that people with a mental illness report (**Empowerment**).

Content of the questionnaire:

- Demographic questions: 16 items
- Internalised Stigma of Mental Illness (ISMI) – 29 items (Ritscher *et al*, 2003)

- Perceived Devaluation and Discrimination Scale 12 items (Link, 1987)
- Boston University (BU) Empowerment Scale – 17 items (Rogers *et al*, 1997)

Results based on 1447 responses - (1223 Valid responses after cleaning of data)

*Analysis of results supervised by Prof. Dr. Marc De Hert (University Hospital Kortenberg University of Leuven, Belgium)*

#### Methodology

- Surveys sent out through the GAMIAN-Europe network of charity organisations in 21 European countries;
- Survey packs translated using forward-back translation approach with reconciliation meeting;
- Survey link sent to each member organisation, with the aim of recruiting a minimum of 50 people

Participating countries: Belgium, Croatia, Czech, Finland, France, Greece, Hungary, Israel, Italy, Lithuania, Luxemburg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Russia, Slovenia, Spain, Sweden

Participants by disorder:

	N	%
bipolar	234	19,13%
depression	237	19,38%
other	176	14,39%
psychosis	325	26,57%
unknown	243	19,87%

#### **Results:**

Results below are First comments, which will have to be confirmed by the academic work of Dr De Herts team.

If possible we have made the comparison between

- All over results and the results of the depression Group
- The results of 2006 and 2010.

#### **Demographic results:**

**Housing situation.** More the 50% of the respondents lived in their own house, flat or apartment, 28 % lived in rented rooms or with relatives. Less than 3 % lived in the hospital.

(There is no significant difference between the all over results and the result for the people with depression)

**Living with.** Most people lived with their family (40% over all, 53% depressed). 25% overall lived with their parents, 20% of the depressed.

**Work.** About 30% declared not to be able to work. 17% overall and 25% of the depressed are reiterd. About 30% had a job (full or part time). Depressed have more full time jobs

**Income.** 25% have a salary, Less than 10% live from contribution from the family. More depressed have a pension (20%/14%)

**Type of care** Only 25% receive in in-patient cares (no difference overall/depressed) More of the depressed receive treatment at home (20%/12%)

ISMI positive responses in %

### ISMI % positive responses

#### From the 29 items scored highest:

Living with mental illness has made me a tough survivor	58,46%
People with a mental illness make important contributions to society.	57,73%
People discriminate against me because I have a mental illness.	52,25%
I am disappointed in myself for having a mental illness.	49,14%
I don't talk about myself much because I don't want to burden others with my mental illness	48,32%

#### From the 29 items scored lowest:

Being around people who do not have a mental illness makes me feel out of place or inadequate.	32,05%
Because I have a mental illness, I need others to make most decisions for me.	31,64%
I cannot contribute anything to society because I have a mental illness.	31,23%
People can tell that I have a mental illness by the way I look.	30,17%
Nobody would be interested in getting close to me because I have a mental illness.	27,56%

### Major differences 2006-2010

People agree less on:

- Most people in my community would treat a former mental patient just as they would treat anyone.
- Most employers will pass over the application of a former mental patient in favour of another applicant

People agree more on:

- Most employers will hire a former mental patient if he or she is qualified for the job.
- Most people would accept a former mental patient as a close friend.

### PPD positive responses

#### Highest scores of 12 items

Most people would not hire a mental health patient to take care of their children, even if she or he had been well for some time	69,34
Most employers will pass over the application of a former mental patient in favour of another applicant.	68,11
Most people think less of a person who has been in a mental hospital.	67,38

#### Lowest scores

Most people believe that a person who has been in a mental hospital is just as intelligent as the average person	45,54
Most people would accept a fully recovered former mental patient as a teacher of young children in a public school	43,99
Most people believe that a former mental patient is just as trustworthy as the average citizen.	43,58

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## **BUES % positive responses**

### **Highest scores of 17 items**

"Making waves" never gets you anywhere.	72,83%
I feel I have a number of good qualities.	72,59%
I feel I am a person of worth, at least on an equal basis with others.	68,66%

### **Lowest scores**

Most of the misfortunes in my life are due to bad luck.	56,55%
Experts are in the best position to decide what people should do or learn.	55,40%
I feel powerless most of the time.	54,83%

## Major differences 2006-2010

People agree less on:

- Experts are in the best position to decide what people should do or learn.

People agree more on:

- I feel powerless most of the time.
- Most of the misfortunes in my life are due to bad luck.

## **Conclusions:**

### **For people suffering from depression/schizophrenia**

33.76% (dep) 47.69% (schi) scores moderate/high on internalised stigma  
43.04% (dep) 47.69 % (schi) score moderate/high on stigma resistance  
67.51 % (dep) 66.77% (schi) scores moderate/high on self esteem/self efficacy  
76.79% (dep) 80.31% (schi) scores moderate/high on power/powerlessness

### **For people suffering from depression difference 2006/2010**

33.76% (2006 = 21.70 %) score moderate/high on internalised stigma  
43.04% (2006 = 59.7%) score moderate/high on stigma resistance  
67.51 % (2006 = 68.3%)score moderate/high on self esteem/self efficacy  
76.79% (2006 = 57.4 %) score moderate/high on power/powerlessness

**The future:**Questions to resolve:

- Do women have lower levels of stigma towards themselves, etc. than men?
- Do people who have a number of relationships in their lives (i.e. have a spouse/partner, live with others, have a friend who they can confide in, are close to their family), have lower levels of stigma towards themselves, etc. than others?
- Do people who are employed, have lower levels of stigma towards themselves, etc., than others?
- Do people who have recently come into contact with mental health services for the first time, have lower levels of stigma towards themselves, etc. than others?
- Do people who agree with their diagnosis, have lower levels of stigma towards themselves, etc. than others?
- Do people who have a diagnosis of a psychotic illness, addiction or personality disorder, have higher levels of stigma towards themselves, etc., than those who have a diagnosis of depression or an anxiety disorder?