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## Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study

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## ABSTRACT

There is a growing interest in examining self-stigma as a barrier to recovery from schizophrenia. To date, no studies have examined mental health service user's experiences of self-stigma throughout Europe. This study describes the level of self-stigma, stigma resistance, empowerment and perceived discrimination reported by mental health service users with a diagnosis of schizophrenia or other psychotic disorder across 14 European countries. Data were collected from 1229 people using a postal survey from members of mental health non-governmental organisations. Almost half (41.7%) reported moderate or high levels of self-stigma, 49.2% moderate or high stigma resistance, 49.7% moderate or high empowerment and 69.4% moderate or high perceived discrimination. In a reduced multivariate model 42% of the variance in self-stigma scores was predicted by levels of empowerment, perceived discrimination and social contact. These results suggest that self-stigma appears to be common and sometimes severe among people with schizophrenia or other psychotic disorders in Europe.

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### 1. Introduction

Self-stigma is a process of identity transformation wherein a person loses their previously held or desired identities e.g. as a partner, friend, parent, employee etc to adopt a stigmatised view of themselves (Yanos et al., 2008). It is one of a range of personal responses to mental illness stigma. Other responses include energisation, righteous anger or no observable response (Corrigan and Watson, 2002). Self-stigma is also referred to as internalised stigma (Van Brakel et al., 2006).

In studies involving participants with a diagnosis of schizophrenia or other psychotic disorders, self-stigma has been associated with reductions in protective psychological variables including hope (Yanos et al., 2008), self-esteem

(Lysaker et al., 2007, 2008; Ritsher et al., 2003; Watson et al., 2007), (Yanos et al., 2008), self-efficacy (Vauth et al., 2007; Watson et al., 2007), empowerment (Ritsher et al., 2003; Vauth et al., 2007), morale (Ritsher and Phelan, 2004) and recovery beliefs (Ritsher et al., 2003). It is associated with lower quality of life (Lysaker et al., 2007; Vauth et al., 2007) and the attribution of personal responsibility to the cause of illness (Mak and Wu, 2006), as well as an increase in avoidant coping strategies, specifically withdrawal and secrecy (Vauth et al., 2007). It has been linked with a reduced likelihood of seeking help from psychological services in a sample of college students (Vogel et al., 2006) and lower psychosocial treatment compliance in those with a diagnosis of depression (Fung et al., 2007).

Clinically, self-stigma is associated with an increase in symptom severity (Mak and Wu, 2006), positive symptoms (Lysaker et al., 2007; Yanos et al., 2008), negative symptoms (Lysaker et al., 2009, 2007) and depressive symptoms

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(Ritsher et al., 2003; Vauth et al., 2007; Yanos et al., 2008), as well as a reduction in insight (Lysaker et al., 2007; Mak and Wu, 2006), social functioning (Lysaker et al., 2007) and attentional functioning (Lysaker et al., 2009).

The above literature highlights the emerging focus on self-stigma as a potential barrier to recovery from schizophrenia. A growing body of work reports on interventions targeted towards reducing self-stigma (Corrigan, 2002; Corrigan and Calabrese, 2005; Corrigan and Watson, 2002; MacInnes and Lewis, 2008; Mak and Wu, 2006; Ritsher and Phelan, 2004; Rusch et al., 2006b; Yanos et al., 2008). Recent work has taken a collaborative approach to investigating service users' experiences of discrimination globally (Thornicroft et al., 2009). However, to date such an approach has not been taken in considering self-stigma. There is an identified need for increased awareness of the burden of mental illness stigma across Europe e.g. (Marusic, 2004). Before considering the utility of self-stigma as a marker of burden of illness, a barrier to recovery and an area for intervention, it is vital to ascertain the degree to which self-stigma is reported across Europe. This study also considered the levels of perceived discrimination, empowerment and stigma resistance across Europe. These additional variables were selected as existing evidence suggests that these variables may be particularly useful to consider in building a picture of self-stigma (Ritsher and Phelan, 2004; Rusch et al., 2006a; Sibitz et al., 2009).

This study aims to (1) describe the level of self-stigma experienced by mental health service users with a diagnosis of schizophrenia or other psychotic disorders in Europe (2) examine the degree to which stigma resistance, perceived discrimination, empowerment and socio-demographic, illness-related and social contact variables are associated with self-stigma in this sample (3) draw implications for European mental health services.

## 2. Materials and methods

### 2.1. Study design

The study had a cross-sectional design where participants completed a postal survey measuring levels of self-stigma, stigma resistance, empowerment and perceived discrimination at one point in time. Surveys were sent through member organisations of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe). GAMIAN-Europe is a patient lead organisation which represents the interests of persons affected by mental illness (GAMIAN-Europe, 2007). Its main objectives include: advocacy, information and education and anti-stigma and discrimination. It includes 74 full member organisations in 32 countries.

### 2.2. Participants

Data were collected in twenty European countries (see Acknowledgments for all participating organisations). The following countries were involved: Belgium, Bulgaria, Croatia, the Czech Republic, Estonia, Finland, France, Greece, Italy, Lithuania, Macedonia, Malta, Poland, Romania, Russia, Slovenia, Spain, Sweden, Turkey and the Ukraine (2 sites). This paper focuses only on data collected from participants with a self-reported diagnosis of schizophrenia or other

psychotic disorders. The study was not restricted to participants with these diagnoses and data from those with other diagnoses will be reported elsewhere. An arbitrary cut-off of 30 cases was used for including sites in descriptive and inferential analyses. This excluded data from Sweden ( $n = 3$ ), Malta ( $n = 25$ ), Finland ( $n = 25$ ), France ( $n = 12$ ), Belgium ( $n = 5$ ), Italy ( $n = 16$ ) and the Ukraine site b ( $n = 25$ ). The remaining 14 sites were included.

### 2.3. Procedure

The study survey was sent to a random sample of 500 people at each study site with the aim of recruiting a minimum of 200 people into the study. The selection of participants was conducted by staff at each study site and was overseen by GAMIAN-Europe. The sample was selected by considering the total membership of the organisation and sending a survey pack to those who appeared at an appropriate number on the membership list (e.g. every third or every tenth). At several sites with a smaller membership, survey packs were also distributed to patients at services run by the organisation e.g. day centers.

The estimate was based on a response rate (50%) achieved in a similar survey study conducted by GAMIAN-Europe (Morselli and Elgie, 2003). Each potential participant was posted a survey pack containing scales which measured self-stigma, stigma resistance, empowerment, perceived discrimination and socio-demographic details. Each pack contained a stamped addressed envelope for the participant to return the survey to the study site. Each pack also contained an information sheet and contact details of the site co-ordinator should the participant wish to ask any questions. The co-ordinator was available to assist the participant with aspects of completing the survey and on occasion, at the participant's request, the survey was completed as a face to face or telephone interview.

### 2.4. Measures

#### 2.4.1. The Internalised Stigma of Mental Illness Scale (ISMI)

The ISMI is a 29-item scale that assesses mental health service users' experiences of self-stigma. It is composed of 5 subscales: alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance. Strong internal consistency ( $\alpha = 0.90$ ) and test-retest reliability ( $r = 0.92$ ) have been reported for the ISMI (Ritsher and Phelan, 2004).

Recent research has suggested that the 'stigma resistance' subscale is conceptually different to the other subscales (Lysaker et al., 2007; Sibitz et al., 2009). For this reason, stigma resistance (SR) is considered as a separate construct to self-stigma throughout this paper. Self-stigma refers to the summed average of the other 4 ISMI subscales.

#### 2.4.2. The Boston University Empowerment Scale (BUES)

Empowerment was measured using the BUES (Rogers et al., 1997). A 17-item version consisting of the self-esteem/self-efficacy (SESE) and power/powerlessness (PP) subscales of the original scale was used in a recent study (Ritsher et al., 2003). Although not formally validated, this version

demonstrated adequate internal consistency ( $\alpha=0.86$ ) and was considered appropriate for use in this study.

#### 2.4.3. The Perceived Devaluation and Discrimination Scale (PDD)

The PDD is a 12-item, unidimensional, scale which measures the extent to which a person believes that most people will devalue or discriminate against someone with a mental illness (Link, 1987). The scale is balanced such that a high level of perceived devaluation and discrimination is indicated by agreement with six of the items and by disagreement with six others. This scale has been widely used and has excellent psychometric properties (Link et al., 1991).

#### 2.4.4. Socio-demographic, illness-related and social contact questions

Participants completed a number of self-report questions on socio-demographic, clinical and social contact variables. Socio-demographic variables included: gender, age, education, housing situation, employment and source of income. Clinical variables included self-reported diagnosis, age at first diagnosis, level of agreement with diagnosis, current treatment status and current main type of mental healthcare. Social contact variables included: living situation, relationship status, level of contact with family, presence of a friend and presence of a confidant or 'best' friend.

#### 2.5. Ethical considerations

Full ethical approval was obtained from the King's College London Research Ethics Committee (ref: CREC/06/07-18). Approval of local ethics committees was obtained in all participating countries.

#### 2.6. Translation procedure

In non-English speaking countries, a consistent translation and cross-cultural adaptation procedure was adopted to ensure that the survey packs were as comparable as possible. All survey materials were translated from English into the target language, ensuring that the translator had the target language as his/her first language, and had English as his/her second language. The translator was provided with background information on the purpose of the study to ensure that a contextual understanding of items was achieved. The site co-ordinator then reviewed the translated survey materials and discussed any problematic translations within the study team to resolve disputed items. This is in keeping with established methods for translation (Sartorius and Kuyken, 1994).

#### 2.7. Data analysis

All analyses were performed using SPSS version 15 and Stata version 9.2.

Descriptive statistics for the socio-demographic, illness-related and social contact variables were calculated. An overall score for the amount of social contact was calculated by recoding the 5 items so that 0 = no social contact and 1 = social contact. A count score was then provided for the number of areas in which social contact was reported (possible range 0–5). Employment was recoded into a binary variable with one category representing working full-time,

part-time, volunteering or student and the other category representing unemployed or retired.

All four study measures (ISMI, SR, PDD, BUES) are scored on a 4-point Likert scale with possible scores ranging from 1 to 4, so that a higher total score indicates a higher level of the attribute. Previous studies have represented a high level of self-stigma as an average score above the midpoint of 2.5 (Ritsher and Phelan, 2004; Ritsher et al., 2003). In this study 4 categories were used: <2 minimal stigma, 2–2.5 low stigma, 2.5–3 moderate stigma and 3+ high stigma. This is a modification of previously used labels (Lysaker et al., 2007). Descriptive statistics were calculated for all scale and subscale scores. The overall internal consistency for each of the four measures and degree of correlation between the four total scores were also calculated.

Analysis of variance (Anova) was applied to the four total scores to examine between-country differences. *T*-test or Anova was also used to examine differences between groups on the basis of gender, education, employment, agreement with diagnosis and current treatment. The relationship between self-stigma (the dependent variable) and the independent variables of: empowerment (SESE), empowerment (PP), stigma resistance, perceived discrimination, level of social contact, gender, employment status, level of agreement with diagnosis, level of education and diagnosis were further explored using clustered univariate and multivariate regression.

### 3. Results

#### 3.1. The sample

1340 surveys were returned from 21 sites. 1229 surveys from 14 sites were included for analysis, excluding 111 surveys from 7 sites where <30 surveys were returned by participants with a diagnosis of schizophrenia or other psychotic disorder. For the 14 included sites, the overall response rate was 72%. Response rates within country ranged from 40% in Sweden to 94% in the Ukraine (site a). There was a midpoint response rate of 75% in Poland. Participants in this sample had a self-reported diagnosis of schizophrenia (73.6%), psychosis (10.8%), other psychotic disorder (9.5%) and schizoaffective disorder (6.1%). 52.6% were male and 23.4% of participants were engaged in some form of work or study. Mean number of social contacts was 3.16 (SD=1.4). Additional socio-demographic information is displayed in Table 1.

#### 3.2. Scoring and scale structure

The internal consistency for the 24-item ISMI was  $\alpha=0.94$ . The SR subscale had an internal consistency of  $\alpha=0.55$ . The other 4 subscales had the following values: alienation ( $\alpha=0.84$ ), stereotype endorsement ( $\alpha=0.75$ ), discrimination experience ( $\alpha=0.79$ ) and social withdrawal ( $\alpha=0.84$ ). The PDD had an internal consistency of  $\alpha=0.84$ . The 17-item BUES had an internal consistency of  $\alpha=0.85$ . The SESE subscale had an internal consistency  $\alpha=0.91$  and the PP subscale had an internal consistency  $\alpha=0.70$ .

Table 2 presents the results of grouping ISMI, SR, PDD, BUES and subscales scores using the minimal, low, moderate and strong categories. This places 41.7% of self-stigma scores in the moderate or high category, 49.2% of stigma resistance

**Table 1**

Socio demographic, illness-related and social contact characteristics of participants.

		N*	%
Gender	Male	647	52.6
	Female	577	46.9
Highest level of education	Primary	143	11.6
	Secondary	861	70.1
	College/university	105	8.5
	Other	89	7.2
Employment status	Full time	114	9.3
	Part time	117	9.5
	Unemployed	638	51.9
	Retired	220	17.9
	Volunteer	18	1.5
	Student	38	3.1
Self-reported diagnosis	Schizophrenia	904	73.6
	Other psychotic disorder	117	9.5
	Psychosis	133	10.8
Agreement with diagnosis	Schizoaffective disorder	75	6.1
	Agree	810	65.9
	Disagree	124	10.1
	Not sure	270	22.0
Age**	Mean (SD)	39.8 (10.7)	
Age at first treatment for mental health problem	Mean (SD)	24.2 (7.6)	
Number of social contacts (range 0–5)	Mean (SD)	3.16 (1.4)	

\* Not all totals equal 1229 (100%) because of missing responses.  
 \*\* n = 3 countries did not collect data on age.

scores, 61.7% of self-esteem/self-efficacy scores, 26.2% of power/powerlessness scores and 69.4% of perceived discrimination scores were in these categories.

There were strong and highly significant correlations between self-stigma and the other measures: ISMI and BUES ( $r = -0.64, p = 0.001$ ), ISMI and SR ( $r = -0.27, p = 0.001$ ), ISMI and PDD ( $r = 0.56, p = 0.001$ ). Degree of social contact was significantly correlated with self-stigma ( $r = -0.35, p = 0.001$ ). Participants who were employed had significantly lower self-stigma scores ( $t = 26.39, p = 0.001$ ). Those who were unsure of whether they agreed with their diagnosis had significantly higher scores than those who agreed (mean difference = 0.24,  $p < 0.001$ ) and those who did not agree with their diagnosis (mean difference = 0.31,  $p < 0.001$ ), (one-way

Anova  $F(2, 1190) = 22.79, p = 0.001$  with Bonferroni adjusted pairwise tests). Those who had tertiary education had significantly lower scores than those who had secondary level education (mean difference =  $-0.18, p < 0.001$ ) (one-way Anova  $F(3, 1180) = 3.93, p = 0.008$  with Bonferroni adjusted pairwise tests). There was also a significant difference in self-stigma scores by gender, with men having lower scores ( $t = 43.58, p = 0.001$ ). Age at first contact with mental health services was not significantly associated with self-stigma.

3.3. Differences between countries

For the 14 included countries, mean self-stigma scores ranged from 2.00 (SD = 0.50) in Slovenia to 2.97 (SD = 0.49) in Greece, with a midpoint mean score of 2.34 (SD = 0.48) in Lithuania. Mean stigma resistance scores ranged from 2.29 (SD = 0.46) in Greece to 2.70 (SD = 0.48) in Lithuania, with a midpoint mean score of 2.48 (SD = 0.48) in the Ukraine. Empowerment scores ranged from 2.43 (SD = 0.32) in Bulgaria to 2.54 (SD = 0.36) in the Ukraine, with a midpoint mean score of 2.49 (SD = 0.39) in Macedonia. Perceived discrimination scores ranged from 2.54 (SD = 0.59) in Romania to 3.34 (SD = 0.42) in Greece, with a midpoint mean score of 2.65 (SD = 0.42) in Spain. There was significant between-country variation on all four measures: self-stigma ( $F(13, 1200) = 23.26, p = 0.001$ ), stigma resistance ( $F(13, 1202) = 5.63, p = 0.001$ ), empowerment ( $F(13, 1213) = 14.83, p = 0.001$ ) and perceived discrimination ( $F(13, 1196) = 27.00, p = 0.001$ ).

3.4. Regression models

Due to the variation between countries described above, univariate and multivariate models in which the significance levels were adjusted using clustering to take account of the differences between countries was included. Table 3 shows the results of these analyses. The variables of SESE empowerment, PP empowerment, PDD and SR were recoded as binary variables so the B coefficient represents the change in ISMI (continuous) when moving from minimal/low to moderate/high levels of each variable. Number of social contacts was also recoded as a binary variable with the B coefficient representing the change in ISMI when moving

**Table 2**

Distribution of ISMI, BUES and PDD score.

	N*	Mean	SD	Minimal >2		Low 2–2.5		Moderate 2.5–3		Strong 3+	
				N	%	N	%	n	%	n	%
ISMI (excludes SR)	1211	2.40	0.56	280	23.0	414	34.0	357	29.4	150	12.3
Alienation (A)	1221	2.53	0.70	324	26.5	325	26.6	306	25.1	266	21.8
Stereotype endorsement (SE)	1215	2.19	0.53	471	38.8	407	33.5	271	22.3	66	5.4
Discrimination experience (DE)	1217	2.43	0.61	366	30.1	266	21.9	450	37.0	135	11.1
Social withdrawal (SW)	1220	2.48	0.66	317	26.0	354	29.0	355	29.1	194	15.9
Stigma resistance (SR)	1216	2.47	0.51	264	21.7	353	29.0	488	40.1	111	9.1
BUES total	1211	2.48	0.41	144	11.9	465	38.4	507	41.9	95	7.8
Self-esteem/self-efficacy (SESE)	1213	2.65	0.57	151	12.4	313	25.8	533	43.9	216	17.8
Power/powerlessness (PP)	1205	2.29	0.44	348	28.9	542	45.0	272	22.6	43	3.6
PDD total	1210	2.79	0.49	65	5.4	305	25.2	497	41.1	343	28.3

\* Not all totals equal 1229 because of missing responses.

**Table 3**  
Combined multiple regression model of self-stigma clustered by country.

Dependent variable is ISMI score		Univariate models (n = 1149–1200)			Multivariate model (n = 1085) Adjusted R <sup>2</sup> = 0.45				
Independent variables		Coeff (B)	95% CI	p*	Coeff (B)	95% CI	p*		
Mod/high SESE empowerment (binary)		<b>−0.50</b>	<b>−0.69</b>	<b>−0.30</b>	<b>&lt;0.001</b>	<b>−0.28</b>	<b>−0.37</b>	<b>−0.19</b>	<b>&lt;0.001</b>
Mod/high PP empowerment (binary)		<b>−0.47</b>	<b>−0.66</b>	<b>−0.28</b>	<b>&lt;0.001</b>	<b>−0.33</b>	<b>−0.42</b>	<b>−0.24</b>	<b>&lt;0.001</b>
Mod/high perceived discrimination (binary)		<b>0.48</b>	<b>0.26</b>	<b>0.69</b>	<b>&lt;0.001</b>	<b>0.31</b>	<b>0.22</b>	<b>0.40</b>	<b>&lt;0.001</b>
Mod/high stigma resistance (binary)		<b>−0.31</b>	<b>−0.54</b>	<b>−0.07</b>	<b>0.016</b>	−0.07	−0.14	0.01	0.077
Increasing number of social contacts (binary)		<b>−0.37</b>	<b>−0.52</b>	<b>−0.23</b>	<b>&lt;0.001</b>	<b>−0.19</b>	<b>−0.27</b>	<b>−0.11</b>	<b>&lt;0.001</b>
Employed (binary)		<b>−0.25</b>	<b>−0.34</b>	<b>−0.16</b>	<b>&lt;0.001</b>	−0.07	−0.15	−0.01	0.064
Diagnosis**									
	Other psychotic disorder	0.25	−0.07	0.58	0.117	<b>0.12</b>	<b>0.04</b>	<b>0.20</b>	<b>0.007</b>
	Psychosis	<b>−0.13</b>	<b>−0.25</b>	<b>−0.00</b>	<b>0.045</b>	−0.04	−0.13	0.05	0.310
	Schizoaffective	−0.24	−0.48	0.01	0.062	−0.10	−0.23	0.03	0.127
Agree with diagnosis***									
	No	−0.33	−0.74	0.08	0.104	−0.13	−0.31	0.04	0.121
	Yes	−0.24	−0.60	0.11	0.160	<b>−0.15</b>	<b>−0.31</b>	<b>0.01</b>	<b>0.053</b>
Non tertiary education (binary)		0.17	−0.06	0.39	0.143	0.02	−0.10	0.14	0.726
Male		0.05	−0.32	0.14	0.201	0.03	−0.04	0.09	0.377

The entries highlighted in bold are significant at  $p \leq 0.05$ .

\* Standard errors are adjusted for clustering (14 countries).  $p =$  value unless  $<$  specified.

\*\* Compared with diagnosis of schizophrenia. There is significant difference by diagnosis  $f_{3/13} = 10.68$ ,  $p = 0.008$ .

\*\*\* Compared with unsure if agree with diagnosis.

from having below the median number of areas of social contact (0,1 or 2) to having the median or higher number of areas of social contact (3,4,5).

When adjusted for clustering by country, the multivariate model predicted 45% of the variance in self-stigma scores. Significant associations were found for moving from minimal/low to moderate/high self-esteem/self-efficacy ( $B = -0.28$ ,  $p < 0.001$ ), moving from minimal/low to moderate/high power/powerlessness ( $B = -0.33$ ,  $p < 0.001$ ), moving from minimal/low to moderate/high perceived discrimination ( $B = 0.31$ ,  $p < 0.001$ ), moving from below the median to median or greater number of social contacts ( $B = -0.19$ ,  $p < 0.001$ ), diagnosis of other psychotic disorder rather than schizophrenia ( $B = 0.12$ ,  $p = 0.007$ ), agree with diagnosis rather than unsure if agree ( $B = p = -0.15$ , 0.053). Moving from minimal/low to moderate/high stigma resistance, currently employed, level of education and gender were not significant independent predictors of self-stigma in this model. A reduced model including only self-esteem/self-efficacy, power/powerlessness, perceived discrimination and social contacts as independent variables predicted 42% of the variance in self-stigma scores.

A multivariate regression model including country as a fixed effect predicted 50% of the variance in self-stigma scores. Similarly to the clustered model, significant associations were found for moving from minimal/low to moderate/high self-esteem/self-efficacy ( $B = -0.28$ ,  $p < 0.001$ ), moving from minimal/low to moderate/high power/powerlessness ( $B = -0.27$ ,  $p < 0.001$ ), moving from minimal/low to moderate/high stigma resistance ( $B = 0.28$ ,  $p < 0.001$ ), increasing number of social contacts ( $B = -0.08$ ,  $p < 0.001$ ), agree with diagnosis rather than don't know ( $B = -0.10$ ,  $p = 0.001$ ). Several additional variables were significant predictors: moving from minimal/low to moderate/high stigma resistance ( $B = -0.07$ ,  $p = 0.005$ ); currently employed ( $B = -0.09$ ,  $p = 0.002$ ), and diagnosis of psychosis rather than schizophrenia ( $B = -0.15$ ,  $p < 0.001$ ). Diagnosis of other psychotic disorder rather than schizophrenia was no longer a significant predictor. In this model

country also had an association when compared with the median scoring country, with two of the other 13 countries having significantly higher scores ( $B = 0.35$ ,  $p < 0.001$ ), ( $B = 0.41$ ,  $p < 0.001$ ) and three significantly lower ( $B = -0.31$ ,  $p < 0.001$ ), ( $B = -0.22$ ,  $p = 0.002$ ), ( $B = -0.21$ ,  $p = 0.003$ ).

#### 4. Discussion

This study primarily examined the degree to which mental health service users with the diagnosis of schizophrenia, psychosis or schizoaffective disorder report self-stigma in 14 European countries. 41.7% of the total sample reported moderate or high levels of self-stigma. The majority of participants felt that the public hold negative attitudes towards mental health service users (69.4% reported moderate to high levels of perceived discrimination) and the degree to which this belief is held was significantly associated with an increase in reported self-stigma in both clustered and unclustered multivariate models.

Empowerment and an increased number of social contacts were both significantly associated with reductions in self-stigma. Within empowerment, 61.7% had moderate to high self-esteem/self-efficacy scores and 26.2% had high power/powerlessness scores. Both subscales had adequate internal consistency.

Stigma resistance was not a significant independent predictor of self-stigma. 49.2% of the sample reported moderate to high levels of stigma resistance which is lower than recently reported levels (Sibitz et al., 2009) but higher than previous reported levels (Lysaker et al., 2008, 2007). All scales had adequate internal consistency with the exception of the stigma resistance subscale ( $\alpha = 0.55$ ). This supports the suggested need for further work to develop this into an independent scale (Sibitz et al., 2009).

In keeping with previous studies, across all sites, participants had the lowest scores for the stereotype endorsement subscale (Lysaker et al., 2008, 2007; Ritsher et al., 2003; Sibitz et al., 2009). This suggests that internalising stereotypes or accepting diminished expectations for oneself e.g. "I cannot

contribute anything to society because I have a mental illness" was not particularly frequently reported, with 72.3% of participants reporting minimal to low levels. Overall, alienation was the most frequently endorsed subscale, followed by social withdrawal and discrimination experience. This is not to say that stereotype endorsement is not an important variable, those with moderate to high levels reported significantly higher levels of the other three subscales. This information may be useful in helping to tailor self-stigma interventions on the elements which are most important to the individual or group involved.

The degree to which programmes need to focus on reducing stereotype endorsement, making sense of perceived stigma and experienced discrimination, or developing social contacts and reducing feelings of alienation and social withdrawal behaviours is an area for further research. The strong relationship between empowerment and self-stigma also suggests that a focus on empowerment may result in self-stigma reductions. However given the cross-sectional nature of our study, this finding would need to be replicated at various timepoints to understand the nature of the association. Mass media campaigns to challenge public stigma e.g. (Henderson and Thornicroft, 2009), also provide an opportunity to examine the degree to which reductions in public stigma are associated with reductions in perceived discrimination and experienced discrimination at several timepoints.

## 5. Limitations of the study

This study was designed to provide evidence on the levels of self-stigma across Europe. As a survey of members of mental health charity organisations, one could argue that these participants are more comfortable with the identity of mental health service user than individuals who are not involved in such activities. It may also indicate that they are adopting a stigma coping strategy based on educating others or on advocacy rather than one based on secrecy or avoidance. Adopting a coping style based on withdrawal or secrecy has been significantly associated with greater self-stigma (Vauth et al., 2007). This suggests participants in our study may have lower self-stigma and higher empowerment than typically present in individuals with this diagnosis. However, it may also be the case that people who experience greater levels of self-stigma may have a higher level of identification with other mental health service users and or may feel more compelled to join in a collective action such as joining a charity organisation. Although it is not possible to compare our scores to others obtained in the countries studied due to a lack of published literature, our scores are comparable with published scores from the US e.g. (Rogers et al., 1997; Vauth et al., 2007).

Surveys were sent to a random sample of 500 members at each charity. There was much variation in response rate with particularly high rates at some sites (94% in one country). Each organisation was asked to reflect on reasons for the response rate at their site. Sites with higher response rates typically had less involvement with research and few participation requests were made to their members. It may be the case that the low response rates in certain countries reflect a level of fatigue with requests for participation in research.

As the study focused on participants with a wide range of diagnosis the number of questionnaires returned by those with a diagnosis of schizophrenia or other psychotic disorders also varied widely by country depending on the nature of the charity e.g. some in some countries where the charity focused on schizophrenia the rate was higher than in charities which focused on mental illness more generally. Data were not weighted to take account of country size, number of returned surveys or other features.

A rigorous translation procedure was applied and acceptable levels of internal consistency were achieved for each language version of each scale. However, our study was limited in its attention to the individual and cultural meanings which participants applied to items. Also within country, linguistic understanding may have varied by education or social class. The benefits of applying a narrative approach to cross-cultural validation of stigma scales has previously been demonstrated (Weiss et al., 2001). Such an approach may add further clarity to the particularly high scores reported by participants in Greece. Previous research has documented the potential for greater public stigma of disability in collectivist cultures such as Greece (Papadopoulos et al., 2002; Westbrook et al., 1993).

## 6. Conclusions

These findings show that self-stigma appears to be common and sometimes severe among people with schizophrenia and other psychotic disorders in Europe. The tailoring of interventions to support the elements of self-stigma which are most problematic for the group, be it alienation, stereotype endorsement, social withdrawal or discrimination experience merits further consideration.

The strong association between self-stigma and empowerment and social contact generates the future hypothesis that interventions to enhance these factors may have a role in reducing self-stigma. It would therefore be beneficial to investigate whether focusing additionally on empowerment and increasing levels of social contact would enhance interventions to alleviate self-stigmatising beliefs.

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### Contributors

EB, RE, NS and GT contributed to the design of this study and writing of the protocol. EB and RE co-ordinated the recruitment of participants. EB undertook the statistical analysis and prepared a first draft of the manuscript. All authors contributed to and have approved the final manuscript.

### Conflict of interest

All authors declare they have no conflicts of interest relevant to the preparation of the manuscript.

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