

GAMIAN-Europe

Pan European Stigma Study

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Internalised stigma

- “ *The product of internalisation of shame, blame, hopelessness, guilt and fear of discrimination associated with mental illness*” (Corrigan et al, 1998);
- Also called felt, imagined or self-stigma (e.g. Van Brakel et al, 2007);
 - Linked with depression, self esteem, perceived legitimacy of discrimination, empowerment, erosion of morale, quality of life, coping, self-efficacy and social functioning (e.g. Ritscher et al, 2003; Vauth et al, 2006; Rusch et al, 2006, Ritscher et al, 2004; Lysaker et al, 2006).



Perceived Devaluation and Discrimination

- Assesses respondents perceptions of what most other people believe about mental illness (Link, 1987);
- the degree to which people with a mental illness believe that the general public hold negative attitudes towards the mentally ill;
- In a cultural context where mental illness is seen as a dominantly negative and relatively powerless identity, those who are labeled in this way and who perceive other people as being rejecting towards them, will experience status loss & discrimination (Link & Phelan, 2001).



Empowerment

“Empowerment can be conceptualised as a process of gaining control over one’s life and influencing the organizational and societal structure in which one lives” (Staples, 1993);

- Three general attributes: self-determination, social engagement and personal competence (Dickerson, 1998).



Aims of GAMIAN Study

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**).



GAMIAN Method

- Surveys sent out through the GAMIAN-Europe network of charity organisations in 20 European countries;
- Survey packs translated using forward-back translation approach with reconciliation meeting;
- Survey pack sent to 500 people at each member organisation, with the aim of recruiting a minimum of 200 people.



GAMIAN-Europe Countries



GAMIAN Method

Each survey pack, contained the following:

- Letter of Invitation
- Participant Information Sheet
- Return Stamped Addressed Envelope
- GAMIAN Europe Pan European Survey containing:
 - Internalised Stigma of Mental Illness (ISMI) – 29 items (Ritscher *et al*, 2003)
 - Boston University (BU) Empowerment Scale – 17 items (Rogers *et al*, 1997)
 - Perceived Devaluation and Discrimination Scale – 12 items (Link, 1987)
 - Demographic questions - 16 items



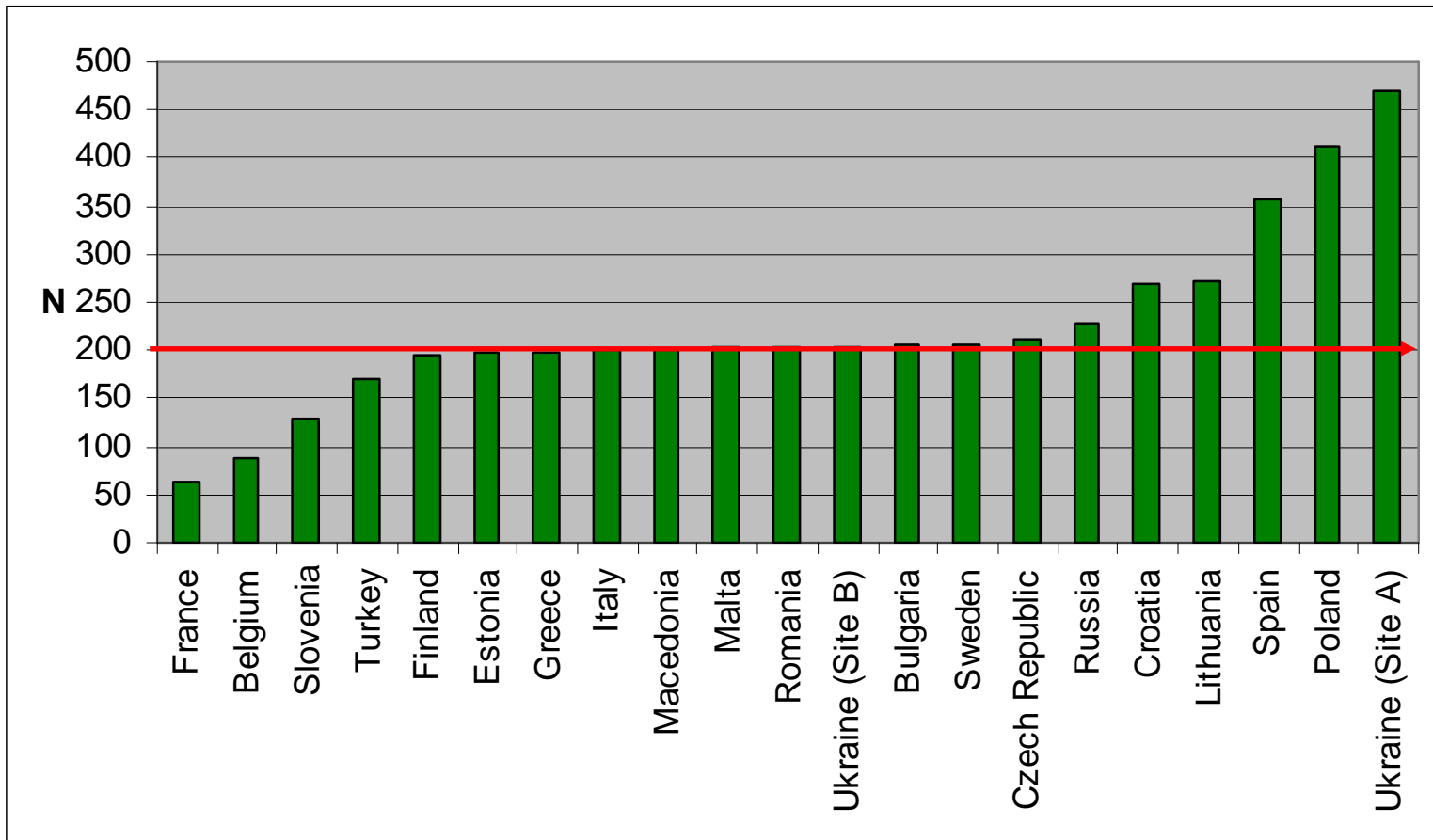
Demographic Questions

16 questions focusing on:

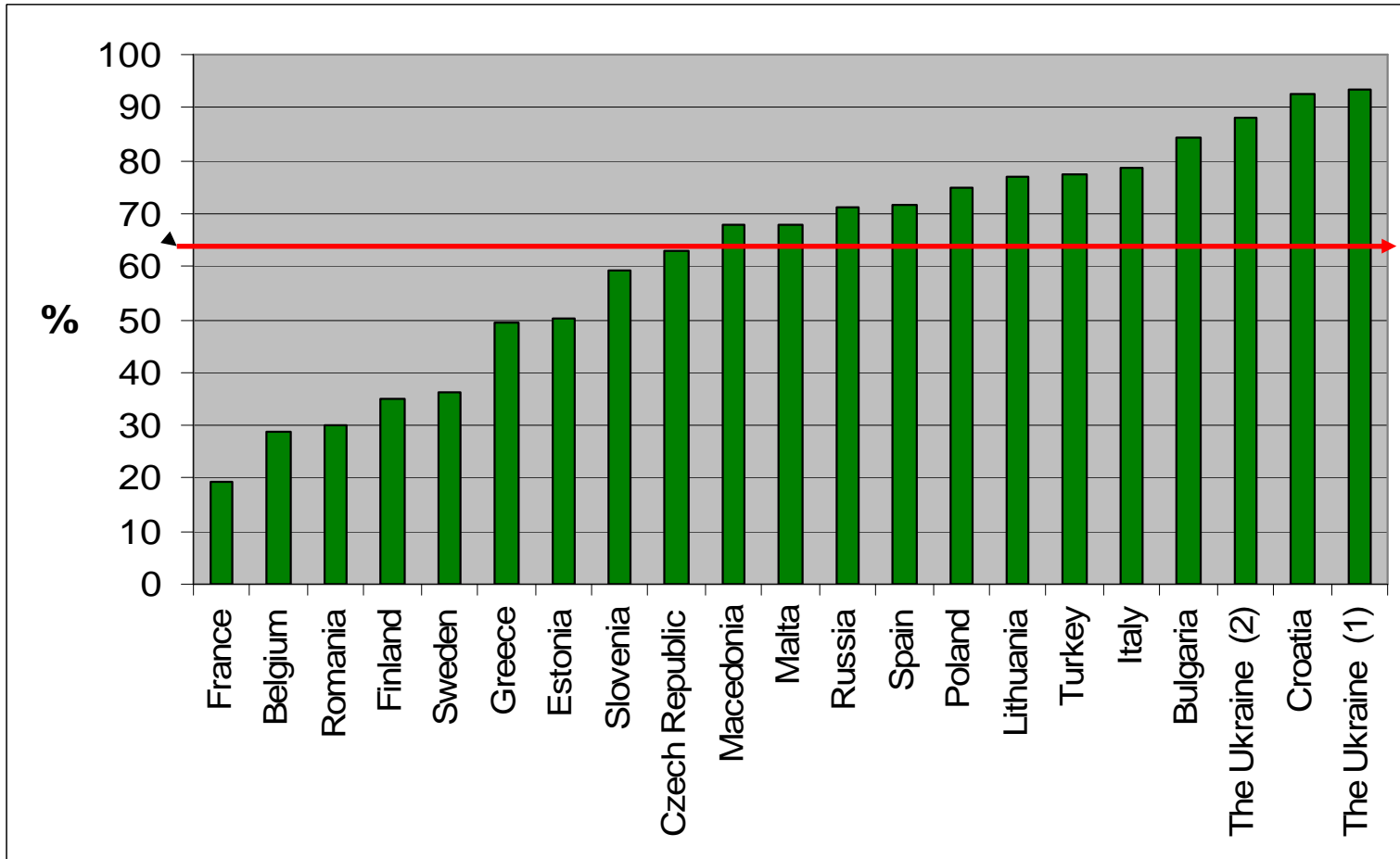
- **socio-demographic information** (gender, age, education, housing , employment, source of income);
- **diagnosis** (do you know diagnosis, age at first diagnosis, agreement with diagnosis, currently receiving treatment, current main type of mental healthcare);
- **social networks** (who do you live with, do you have a partner, is there someone you think of as a friend, do you have a “best friend” to confide in, are you close to anyone in your family).



Data Collected by Country



Response rate by country



Why such differences?

- Choosing participants
- How was the survey conducted?
- Information on the members of your organisation?
- How many staff work at your organisation?
- What types of treatment are available for mental illness?
- How many other surveys has your organisation taken part in, in the past 2 years?
- Please list any surveys which you are aware of that have estimated the rate of mental illness?



Results – Socio demographic

Item	Response Options	N	%
Gender	Male	2153	46.3%
	Female	2495	53.7%
Age	Mean (SD)	42.07 years (12.41)	
Education	Primary	639	14.2%
	Secondary	1952	43.4%
	College/University undergraduate	992	22.0%
	University postgraduate	550	12.2%
	Other	368	8.2%
Housing situation	Own house, flat or apartment	2572	56.4%
	Rented room(s)	541	11.9%
	Live with relatives or others	821	18.0%
	Homeless shelter	25	.5%
	Hospital	325	7.1%
	Residential care home	147	3.2%
	Other	127	2.8%



Results – Socio demographic

Item	Response Options	N	%
Do you work?	Full time	797	18.8%
	Part time	438	10.3%
	Volunteer	103	2.4%
	Looking for a job	559	13.2%
	I'd like to work but am afraid of losing benefits	178	4.2%
	Not able to work (disabled)	964	22.7%
	I choose not to work (either paid or voluntary)	171	4.0%
	Student	152	3.6%
	Retired	883	20.8%
Where does your money come from?	Salary or wages	1099	24.0%
	Disability payments	1677	36.7%
	A pension	895	19.6%
	Financial contributions from the family	516	11.3%
	Charitable grants/donations	34	.7%
	Other	350	7.6%



Results – Social Network

Item	Response Options	N	%
Who do you live with?	My girlfriend, boyfriend, partner or spouse	1383	29.8%
	My children	430	9.3%
	My parent(s) or relative(s)	1470	31.7%
	Friends	88	1.9%
	Roommates	320	6.9%
	I live alone	838	18.1%
	Other	103	2.2%
Do you have a girlfriend/boyfriend, partner or spouse right now?	Yes	2098	46.1%
	No	2451	53.9%
Of the people who you see often, is there someone you think of as a friend?	Yes	3350	76.6%
	No	1025	23.4%
Do you have a best friend you can confide in?	Yes	2971	65.0%
	No	1600	35.0%
Are you particularly close to anyone in your family?	Yes	3477	76.6%
	No	1061	23.4%

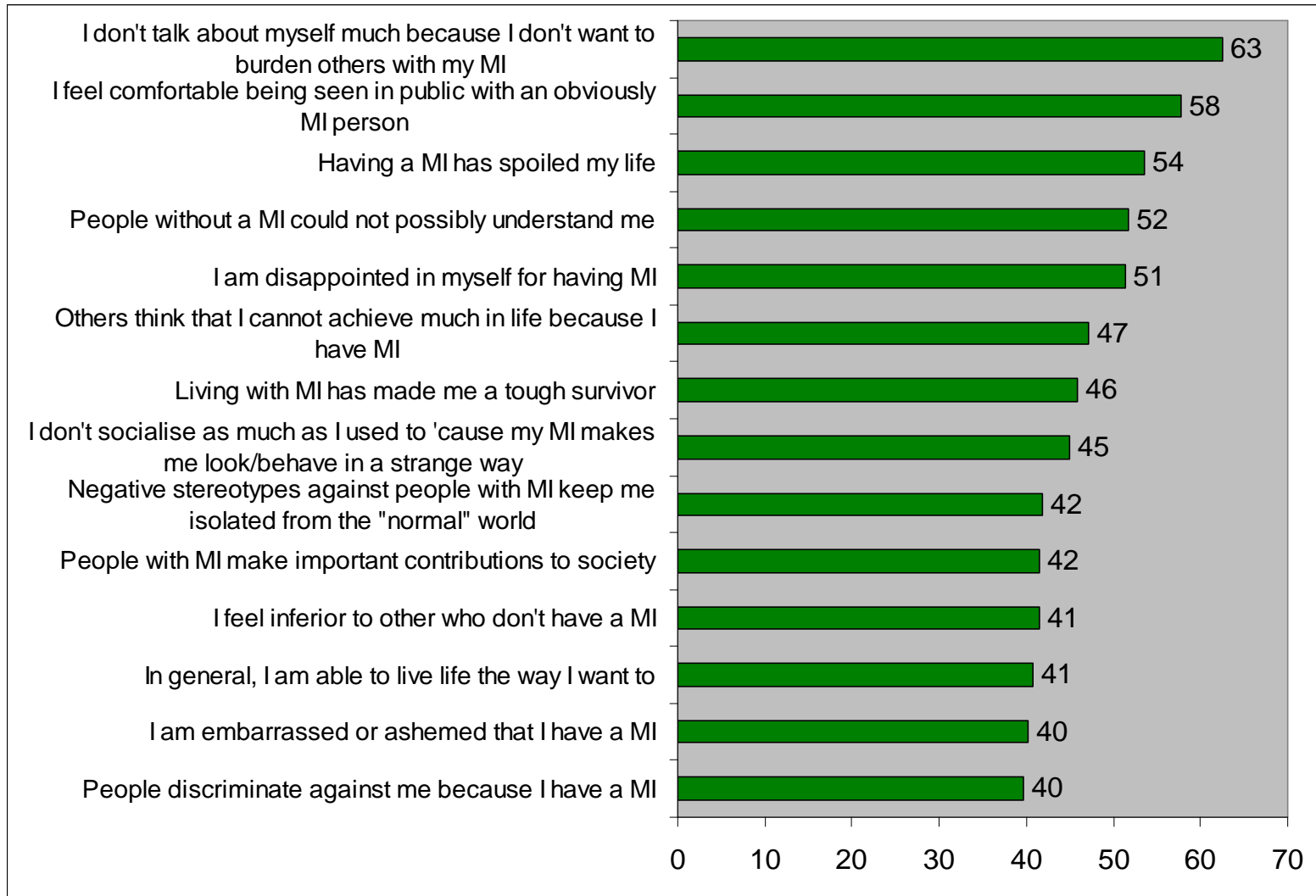


Results - Diagnosis

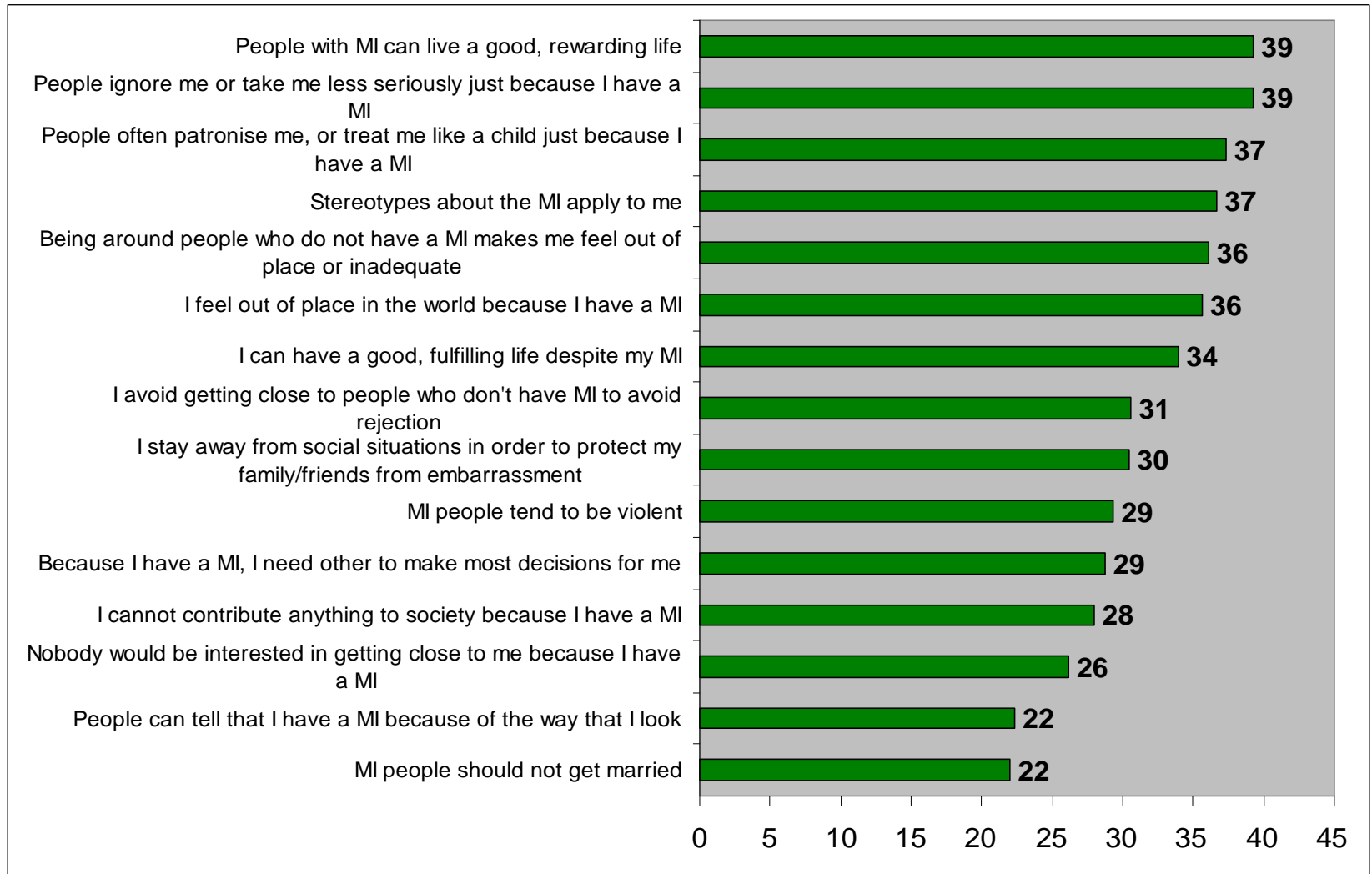
Item	Response Options	N	%
Do you know what diagnosis your doctor has made in your case?	Yes	3448	77.3%
	No	1010	22.6%
How far do you agree with your diagnosis?	Agree fully	2238	53.1%
	Agree partially	899	21.3%
	Disagree fully	207	4.9%
	Not sure	869	20.6%
How old were you when you first received treatment for a mental illness (years)?	Mean (SD)	28.24 years (11.57)	
Are you currently receiving treatment for a mental illness	Yes	2993	92.1%
	No	257	7.9%
What is your current main type of mental healthcare?	In-patient care	55	32.3%
	Out-patient care	51	39.9%
	Treatment at home	47	15.5%
	Day care	6	6.5%
	Other	12	5.7%



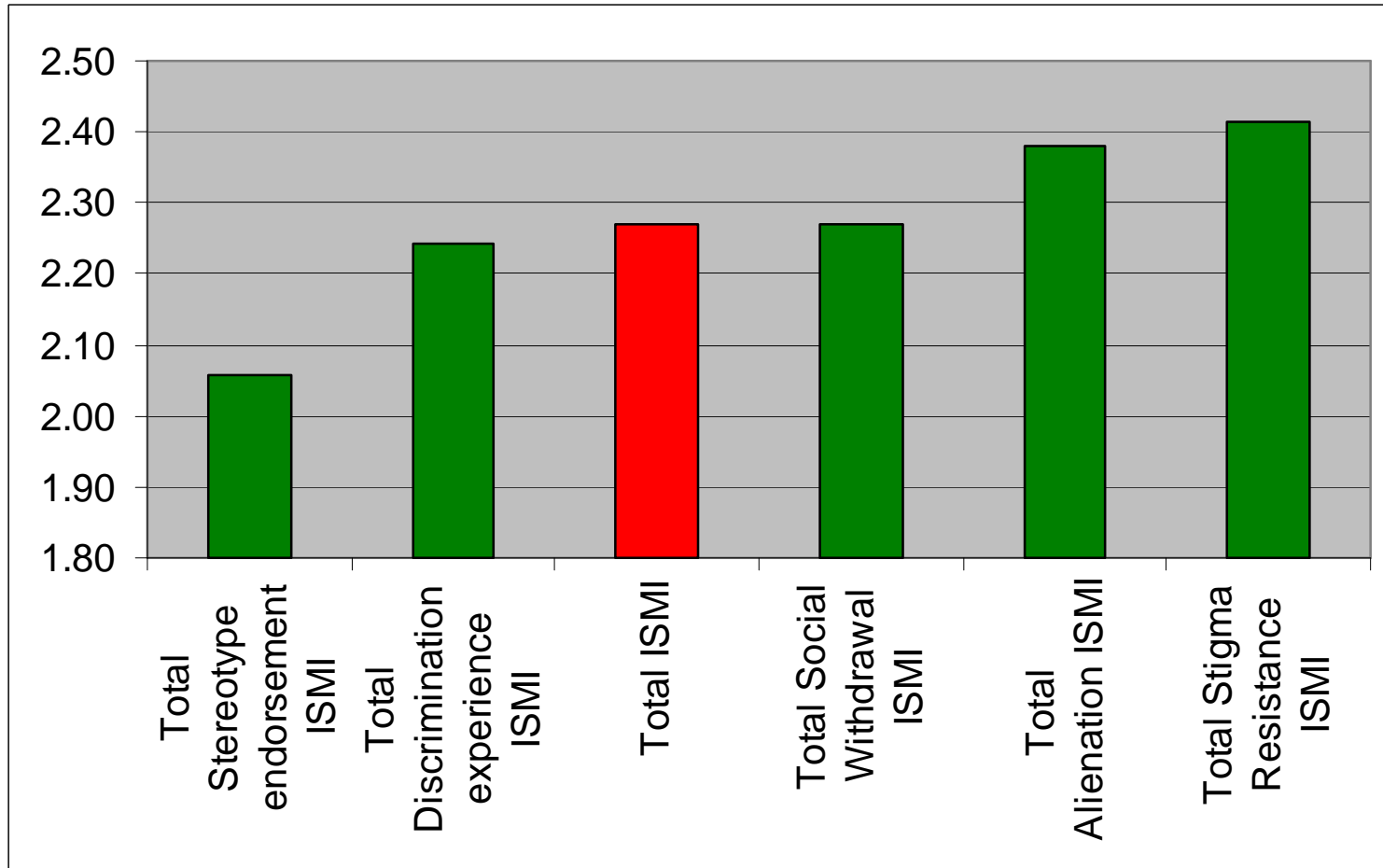
ISMI - % positive responses



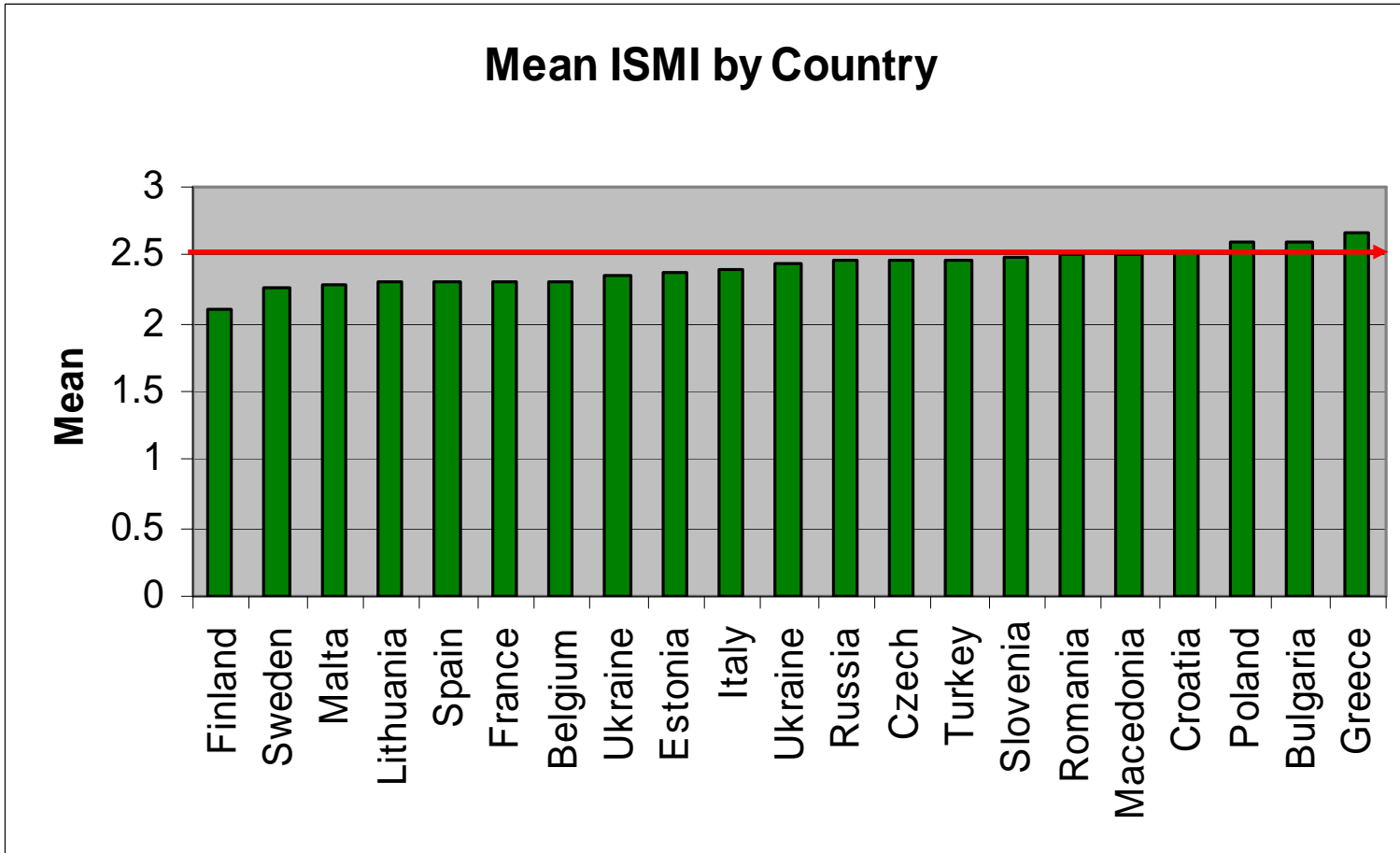
ISMI - % positive responses



ISMI Subscales



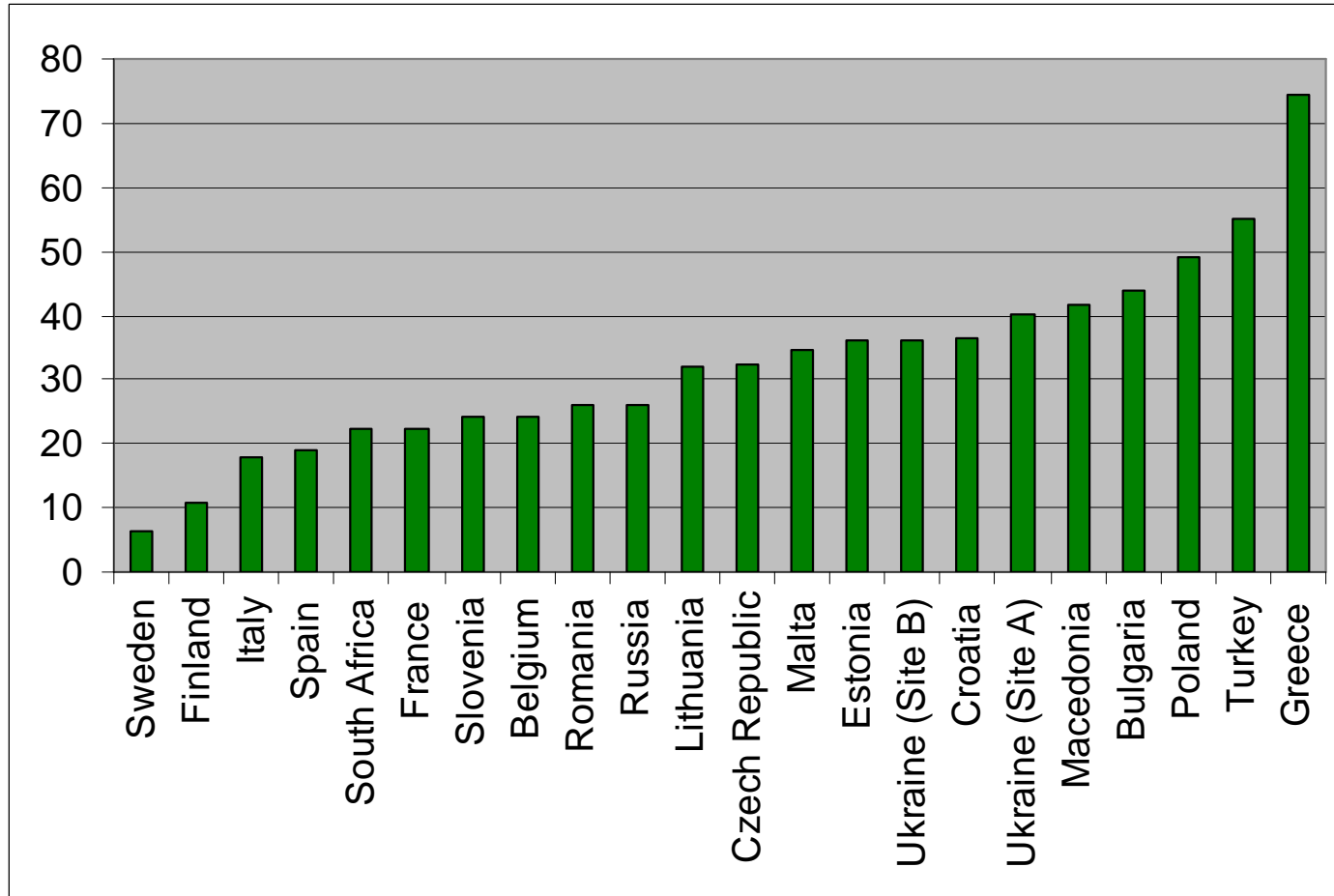
Mean ISMI



Overall mean
= 2.28



ISMI



Ranges
from 6% in
Sweden to
74% in
Greece

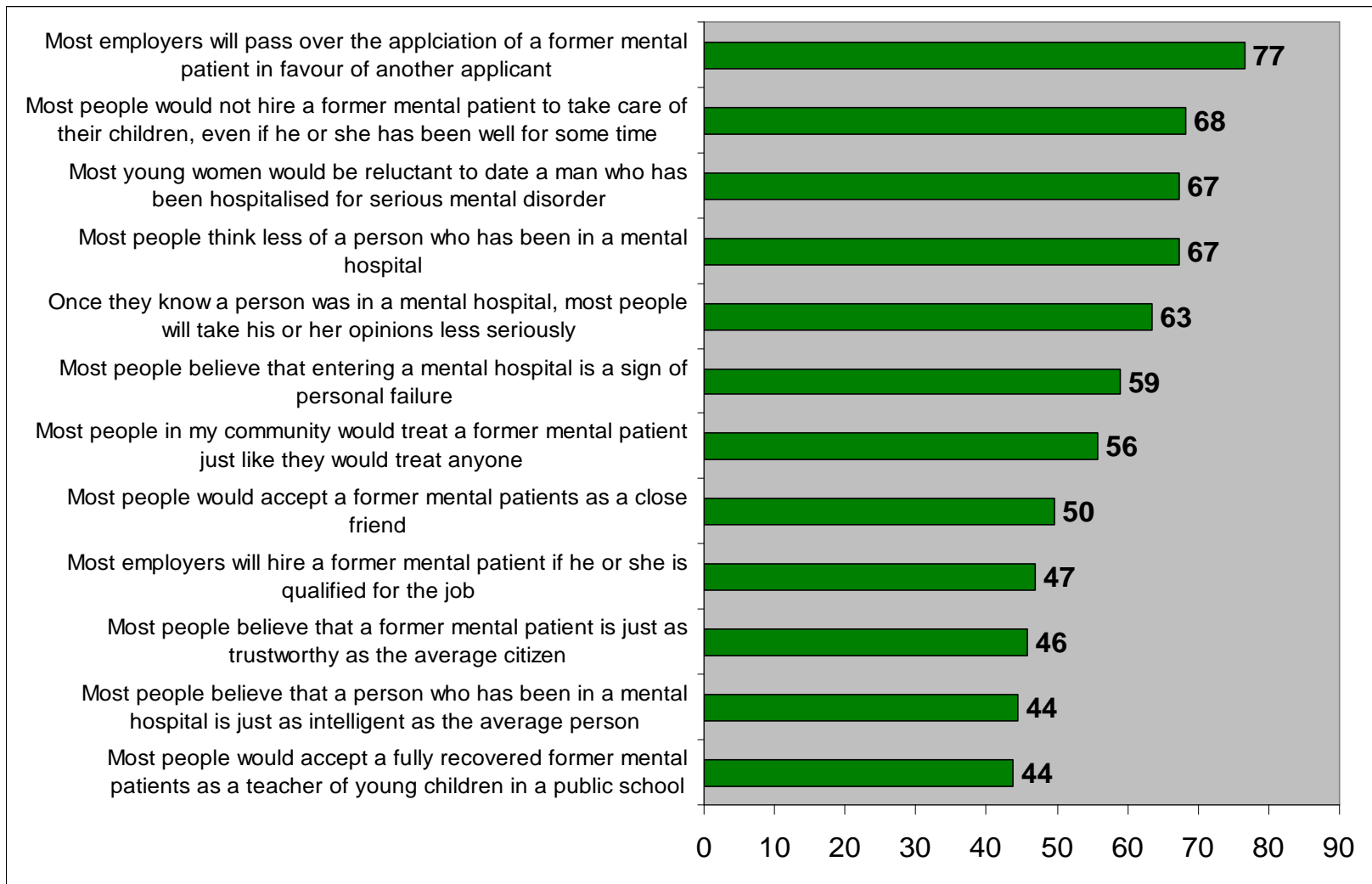


Interpretation of ISMI scores

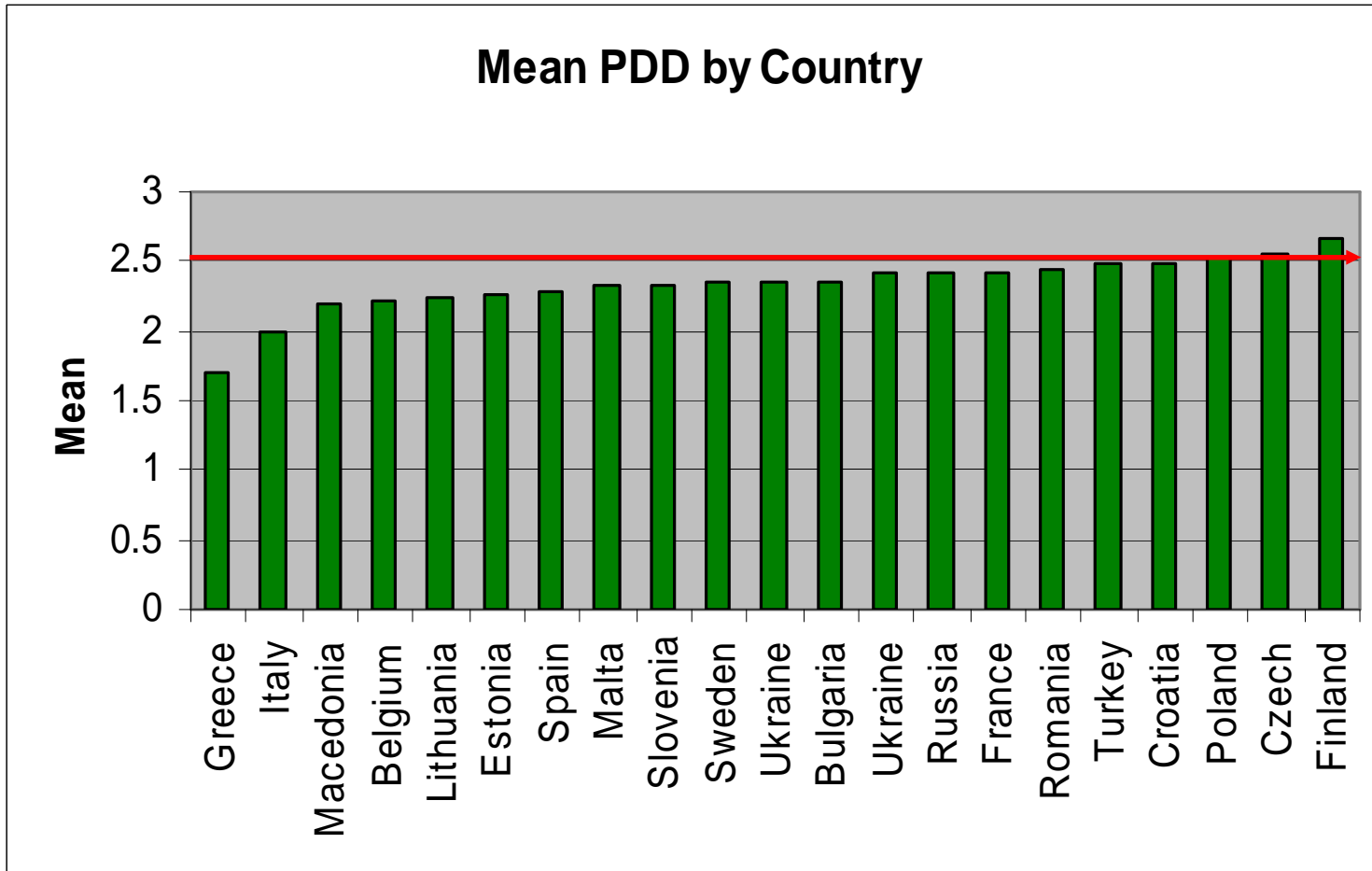
- Overall, 33.4% of valid ISMI scores are above possible median for the scale. For most, moderate levels of internalised stigma are apparent;
- There is large variability in this by country with 6% of responses in Sweden to 74% in Greece, above the median;
- The highest endorsed sub-scale is stigma resistance and the lowest is stereotype endorsement.



PDD - % positive responses



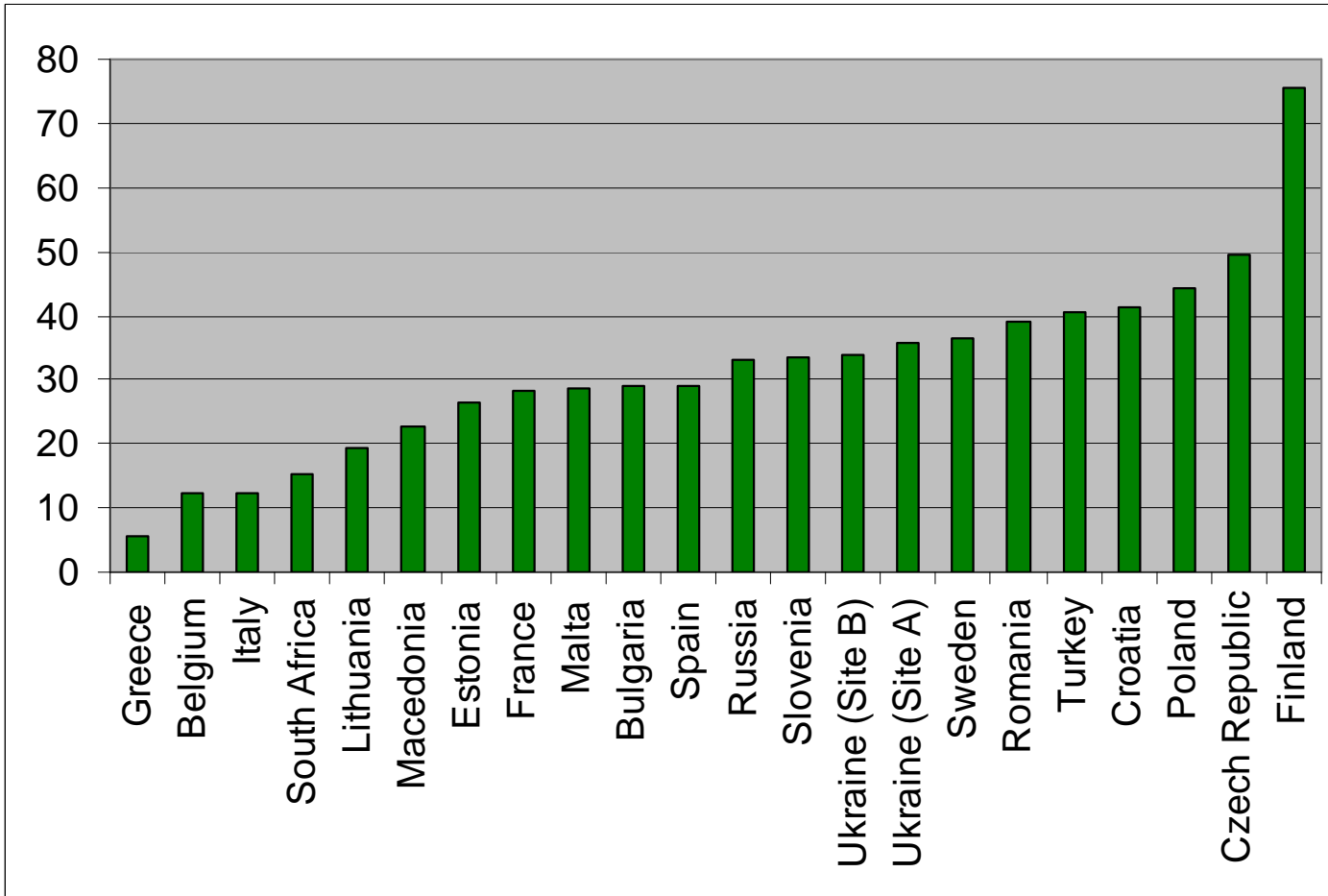
Mean PDD



Overall mean
= 2.34



PDD



Ranges from 6% in Greece to 75% in Finland

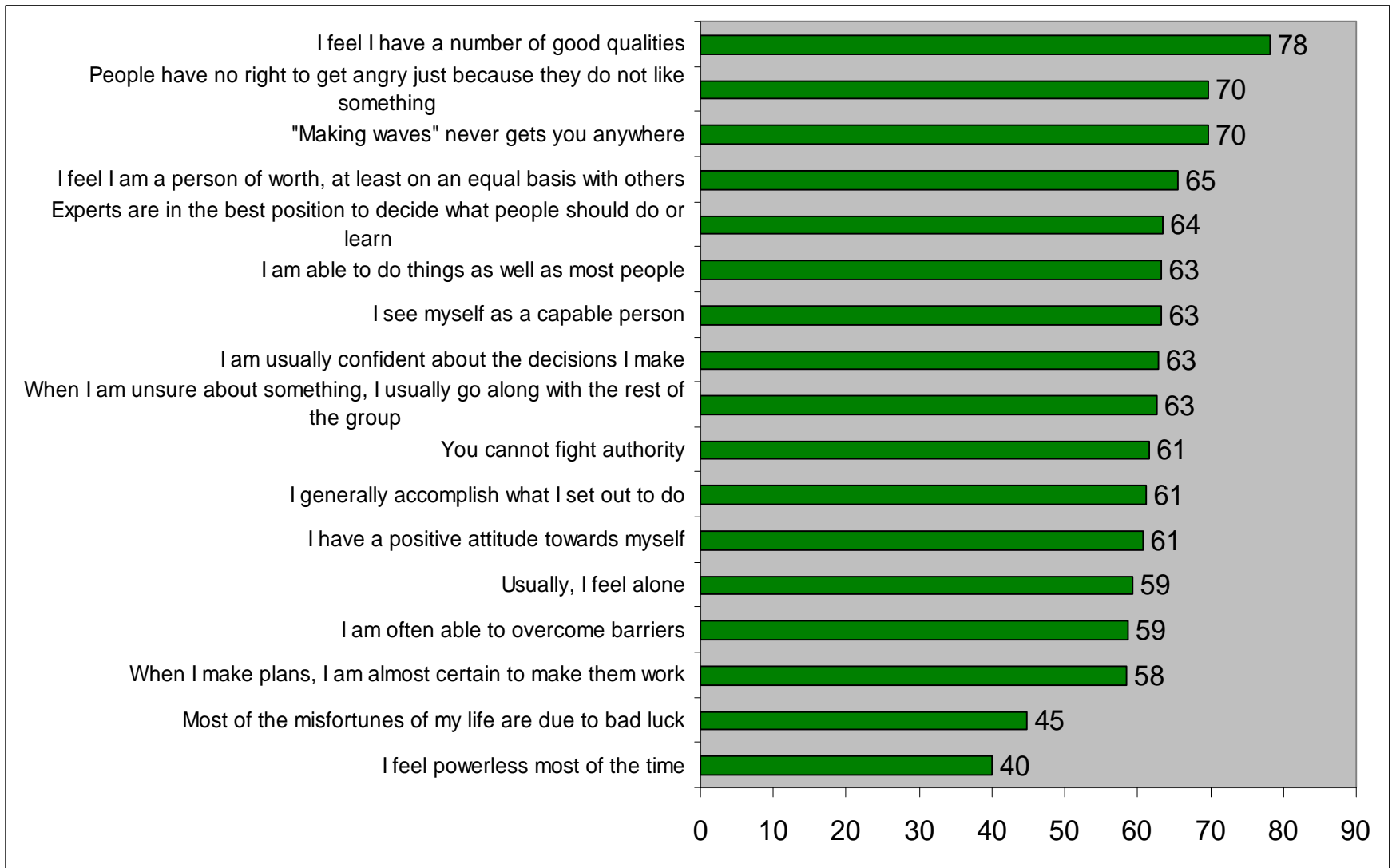


Interpretation of PDD scores

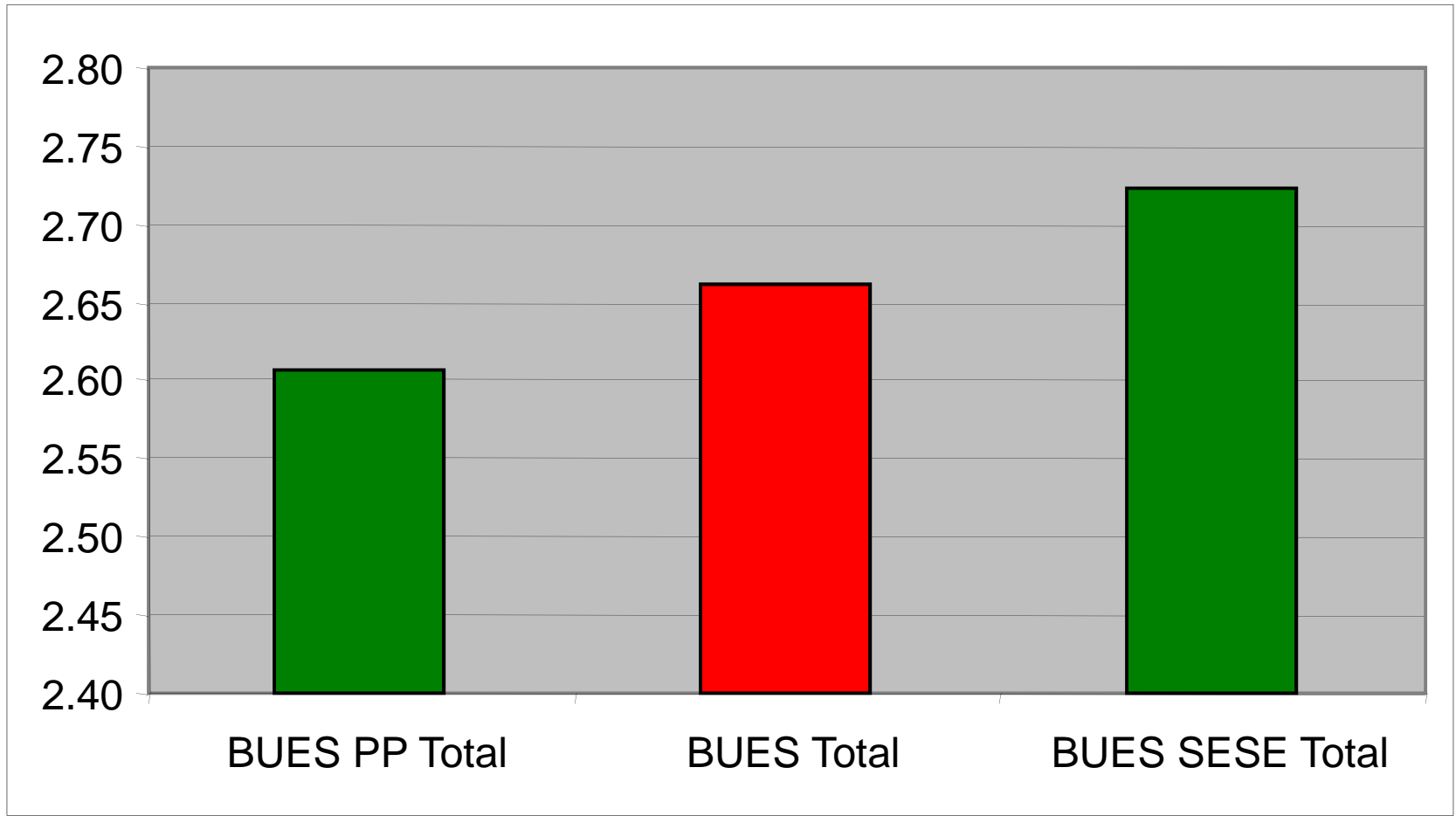
- 32.6% of valid scores are above possible median for the scale. For most, moderate levels of perceived devaluation discrimination are apparent;
- There is large variability in this by country with from 6% in Greece to 75% in Finland;
- At an item level, very high responses for individual items, especially in relation to employment.



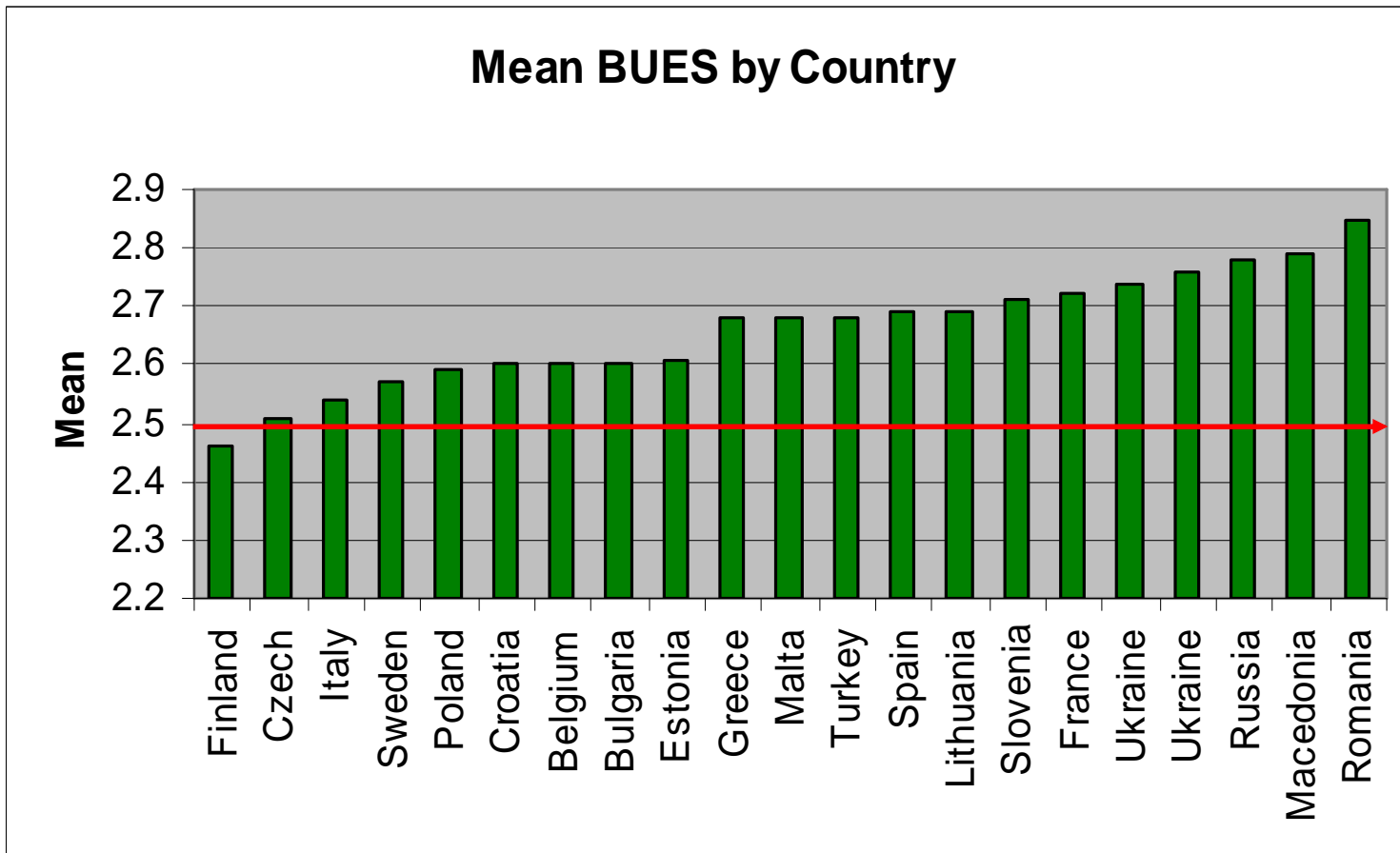
BUES - % Agreement



BUES Sub-scores



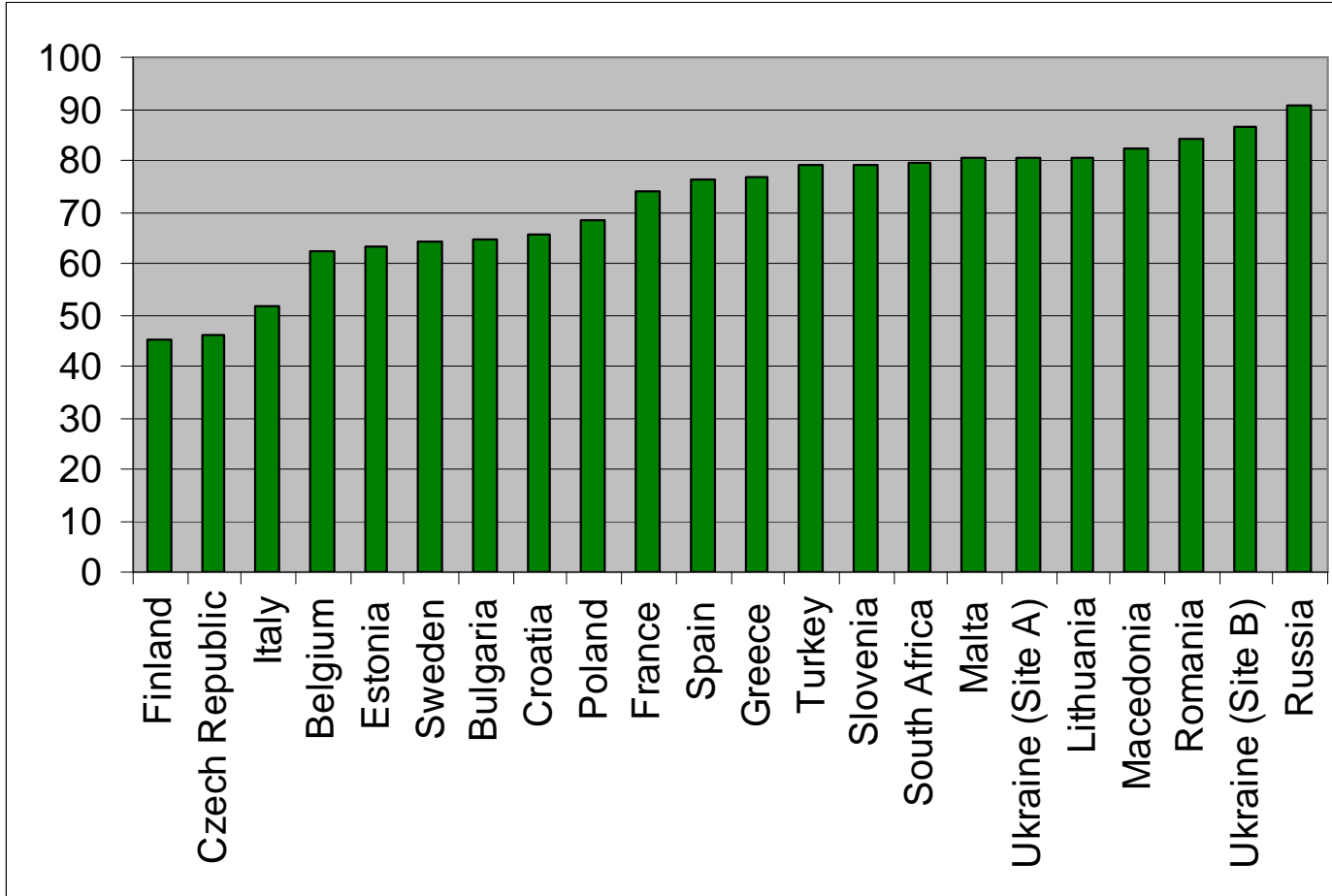
Mean BUES



Overall mean
= 2.66



BUES



Ranges
from 45%
in Finland
to 91% in
Russia



Interpretation of BUES scores

- Overall, 72.41% of BUES scores are greater than the possible median. This indicates high empowerment;
- Variability by country ranges from 45% in Finland to 91% in Russia;
- Scores on the self-esteem/self-efficacy subscale are higher than those on the power/powerlessness subscale.



Summary

- Moderate levels of internalised stigma was apparent in all countries. Highest scores were seen in stigma resistance variables, the lowest level was seen in stereotype endorsement variables;
- High levels of empowerment were apparent in all countries. Highest scores were seen in the self-efficacy/self esteem items;
- Moderate PDD was reported, with notably high item levels on employment variables.



Summary

- There is much variability by country on the three survey measures – this will be explored in our further work;
- The high levels of empowerment possibly point to the nature of our sample, i.e. all are members of mental health charity organisation.



Questions that we will answer

1. Do people who believe that the general public hold negative attitudes towards the mentally ill, have higher levels of stigma towards themselves than those who do not?
2. Do women have lower levels of stigma towards themselves, etc. than men?
3. 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?
4. Do people who are employed, have lower levels of stigma towards themselves, etc., than others?



Questions that we will answer

5. 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?
6. Do people who agree with their diagnosis, have lower levels of stigma towards themselves, etc. than others?
7. 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?

