



# Patients' views on adherence to treatment in schizophrenia

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Aims and development of the survey

# Background

# The 2012 GAMIAN-Europe survey

- GAMIAN-Europe, a patient-driven pan-European organisation, represents the interests of persons affected by mental illness and provides:





# GAMIAN-Europe Surveys

**GAMIAN-Europe endeavors to capture patient views through surveys sent out through the network member associations**

Translated survey packs posted online on the GAMIAN website, Facebook, Twitter and LinkedIn pages



Stigma (2006  
and 2010)

Physical and  
mental health  
(2011)

Adherence to  
treatment  
(2012)

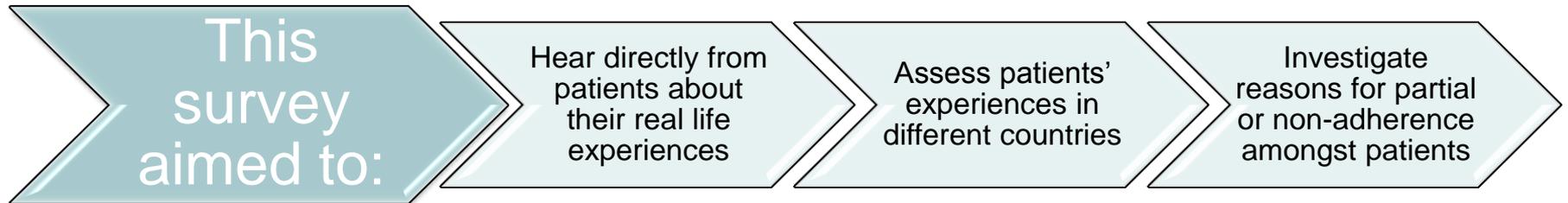
Mental Health  
and workplace  
(2013)

# The need to understand the patients' perspective of adherence (2)

- There are a range of patient-, treatment-, environment- and physician-related factors that contribute to partial and/or non-adherence to medication in patients with schizophrenia<sup>1-3</sup>
- Understanding poor adherence from a patient perspective may help to identify ways to address adherence more effectively

# Aims of the survey

- In 2012 GAMIAN-Europe conducted a survey on adherence to treatment amongst patients with schizophrenia



- The survey results are intended to be circulated amongst National and EU policymakers
  - With the aim of improved integration of mental and physical healthcare for patients living with mental health disorders

# Development of the survey

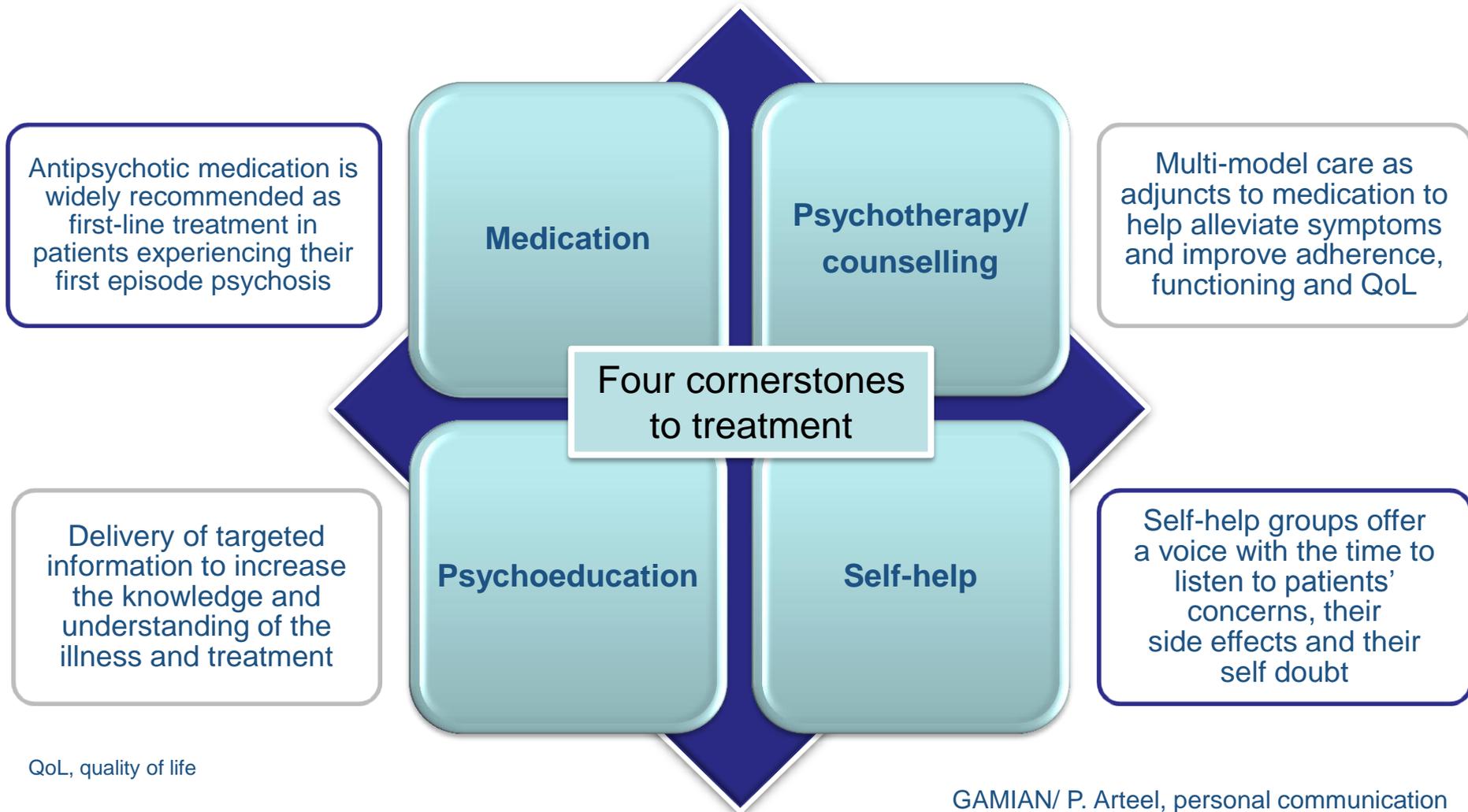
- The survey was compiled by a steering committee of patient representatives and academics:

Who?	• Patients
How many?	• 403
Where?	• 18 countries (GAMIAN website)*
When?	• April – July 2012
Poster presented at:	• ECNP (October 2012)

- Questions were designed to assess patients' experiences of:
  - Medication
  - Psychotherapy/counselling
  - Psychoeducation
  - Self-help initiatives

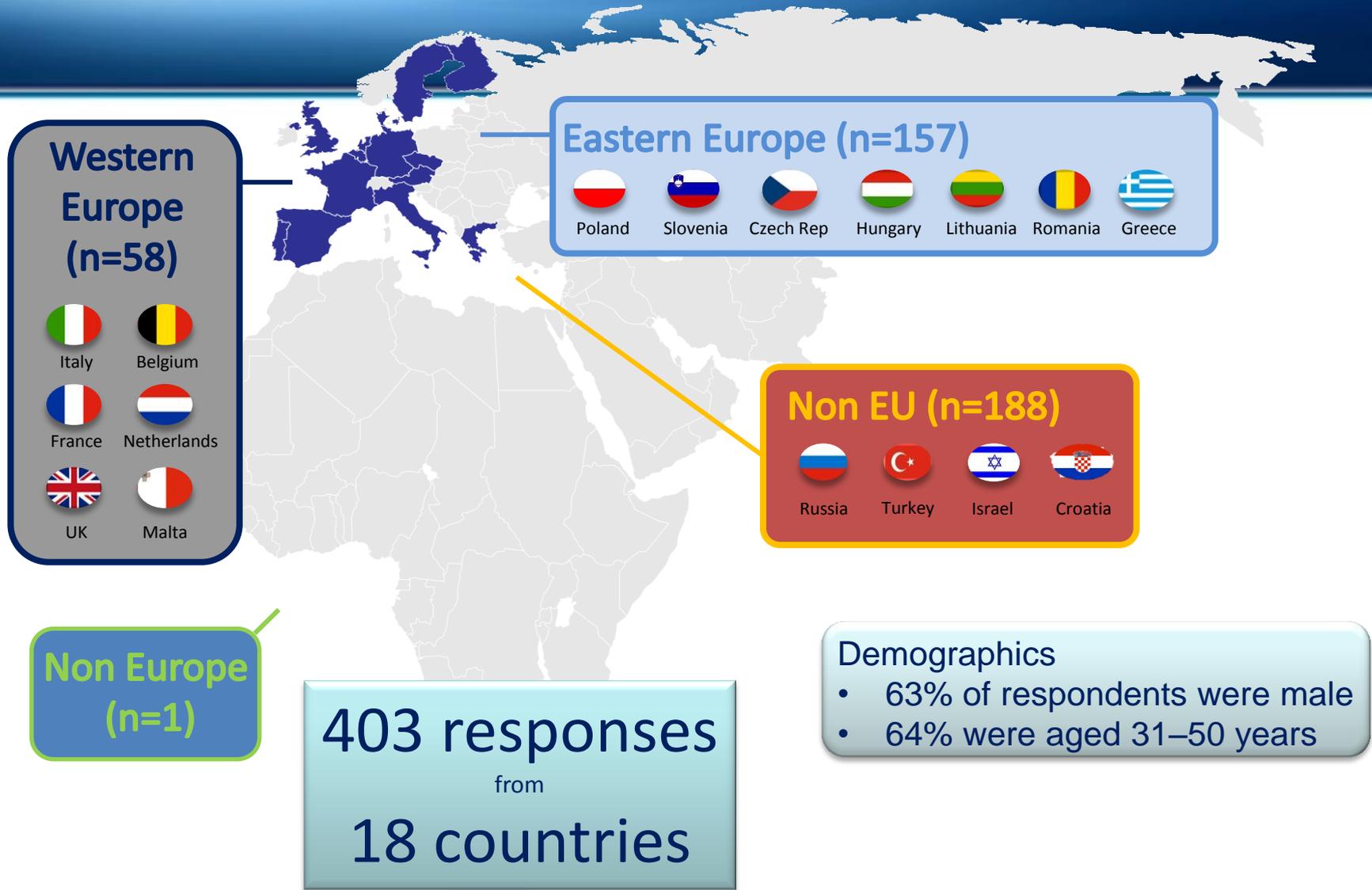
\*The survey could also be downloaded and completed copies returned by post

# Adherence to treatment is more than adherence to medication

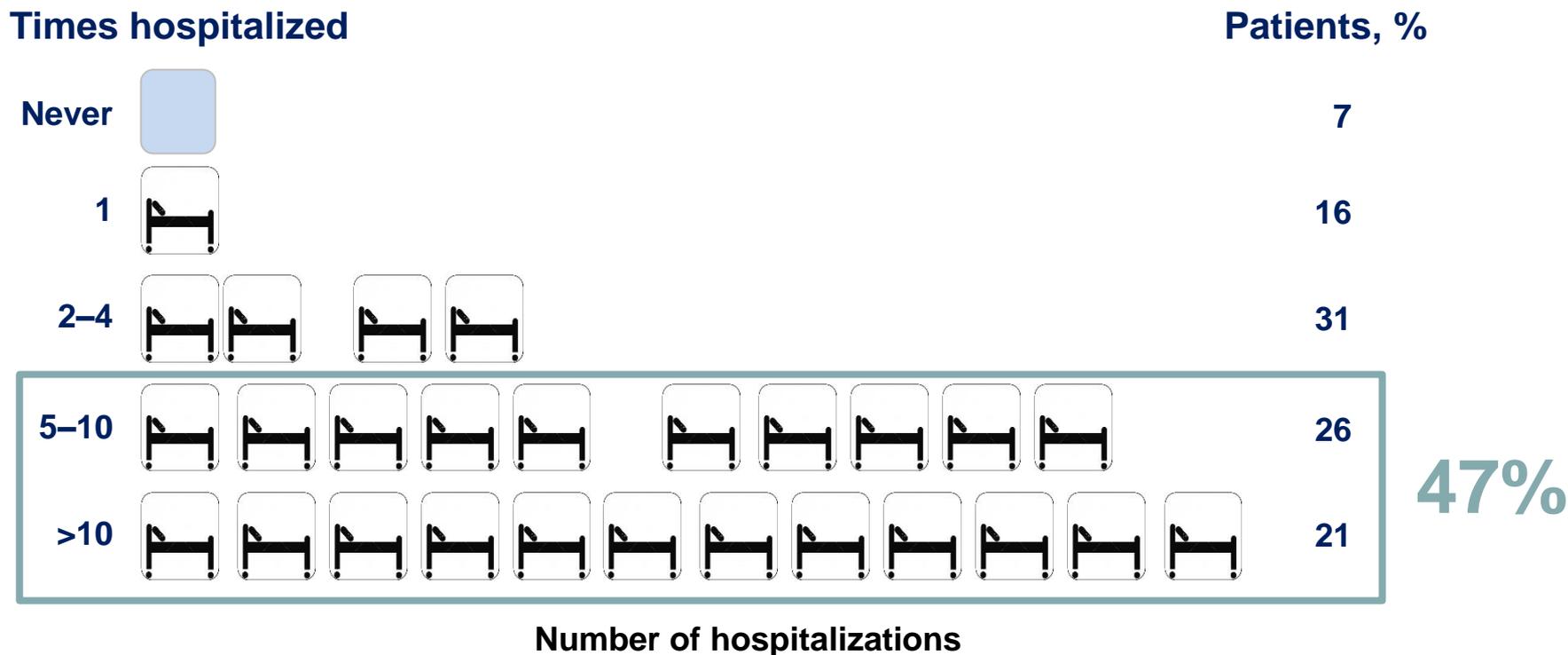


# **Background of respondents**

# Patient survey: the demographics

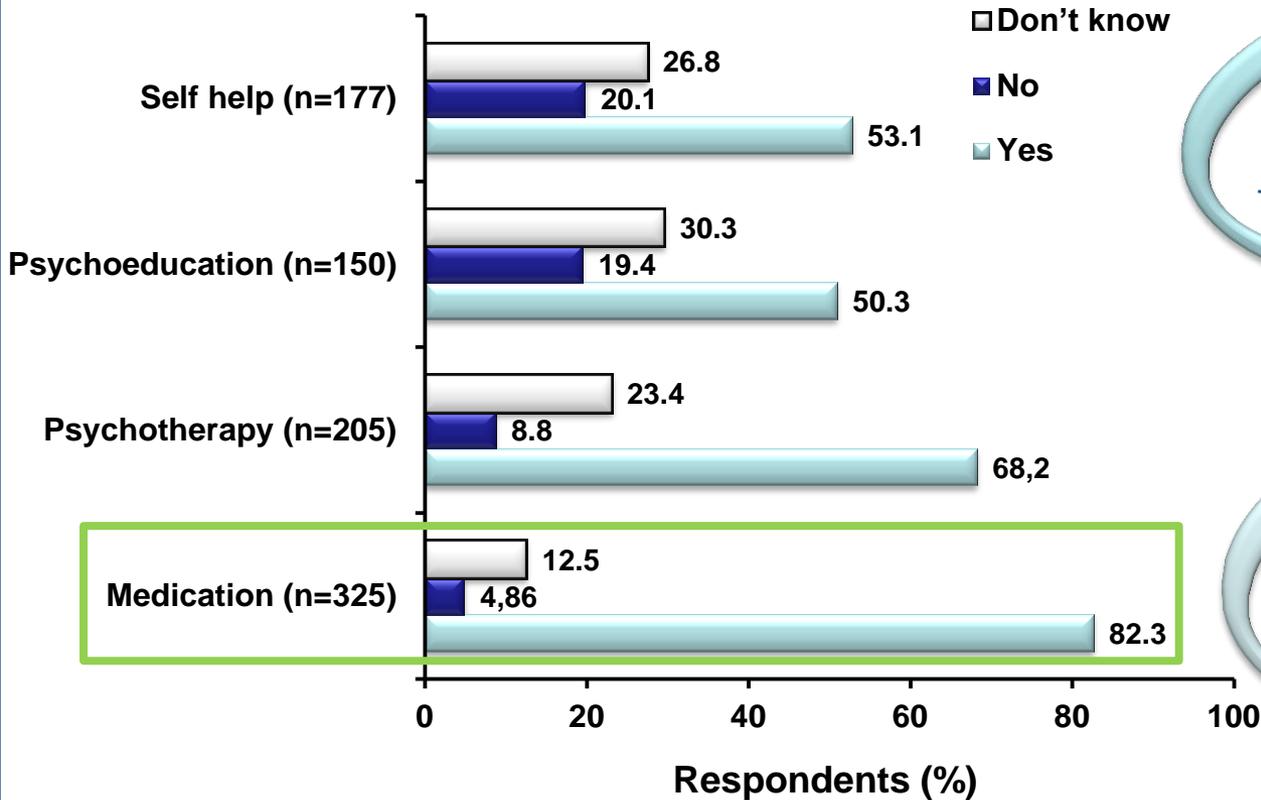


# 47% of respondents had been hospitalized five times or more



Fewer patients from WEU (38%) than EEU (47%) were hospitalized five times or more

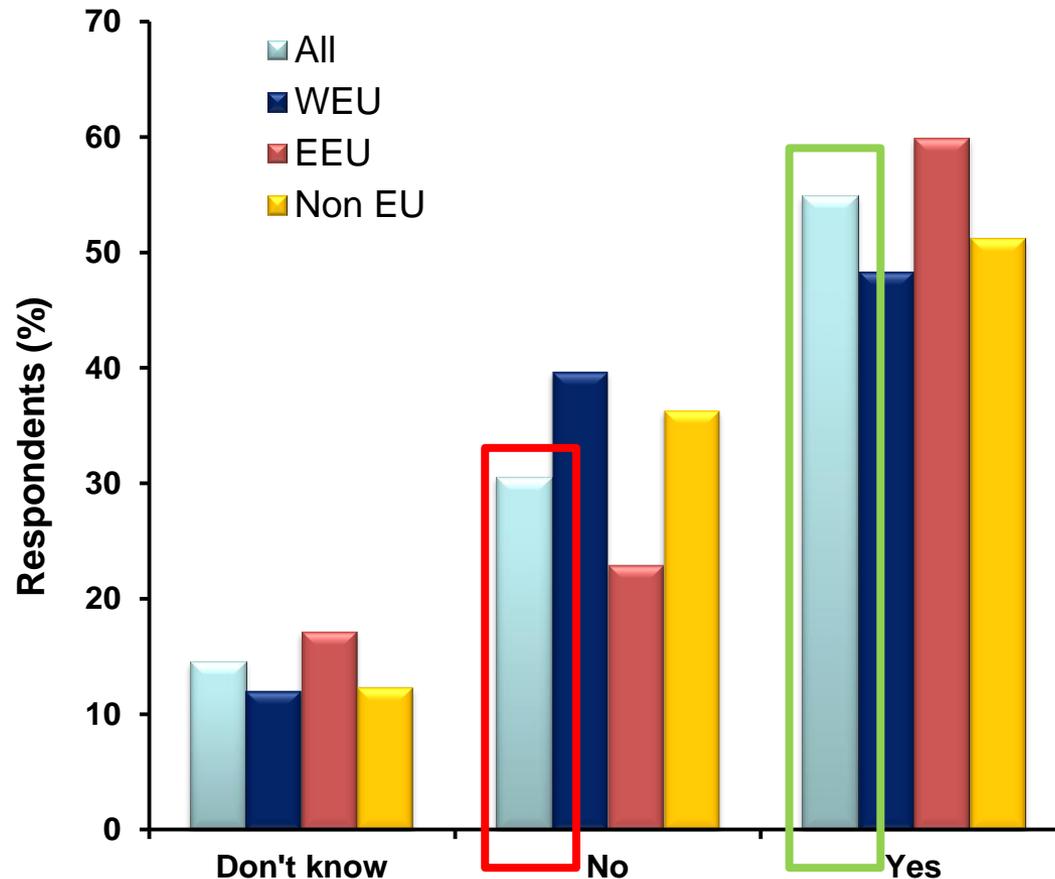
# Most respondents believe it is important to take treatment as prescribed



Majority of respondents believed it is important to take treatment as prescribed

Responses varied according to treatment type, with strongest agreement on the importance of medication

# Many patients did not consider themselves well informed about treatment options



50% of respondents thought themselves to be well informed about possible treatment options

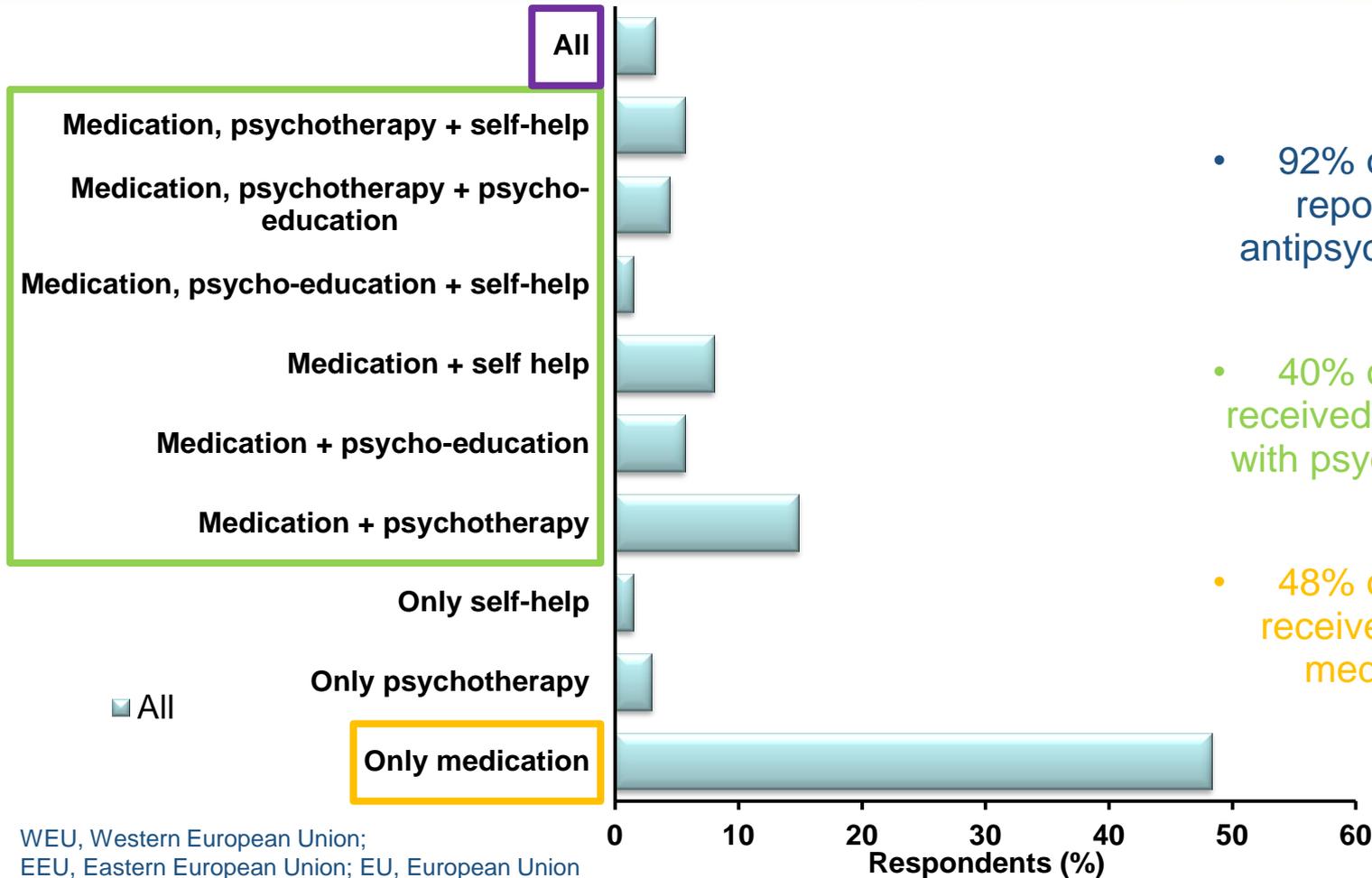
37% did not consider themselves well informed

WEU, Western European Union;  
EEU, Eastern European Union; EU, European Union

Q/ Were you well informed on possible treatment options?

Gauci et al. Poster presented at ECNP,  
13–17 October 2012, Vienna, Austria; GAMIAN/ P. Arteel, personal communication

# Fewer than 4% of patients receive the 'best package of care' as considered by GAMIAN-Europe



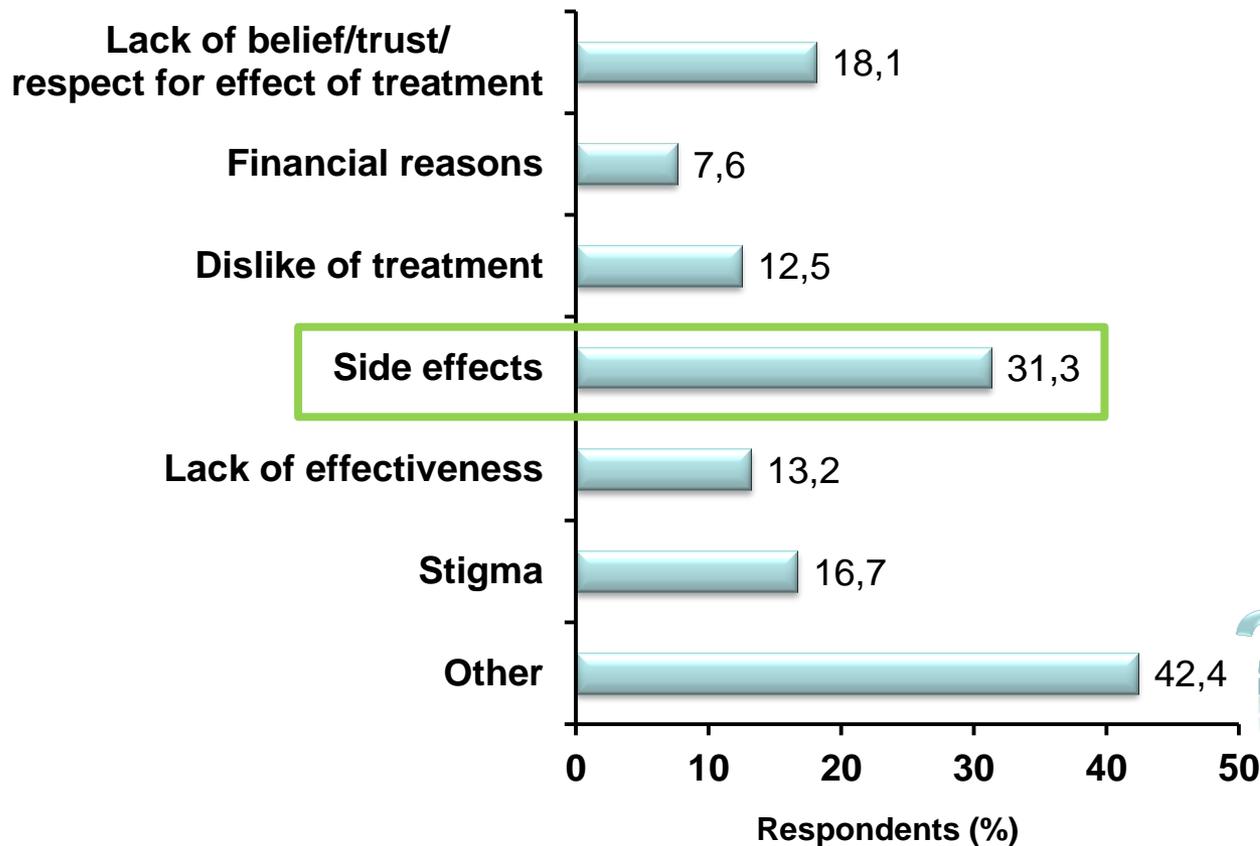
- 92% of respondents reported receiving antipsychotic medication
- 40% of respondents received medication along with psychosocial therapy
- 48% of respondents received antipsychotic medication alone

WEU, Western European Union;  
EEU, Eastern European Union; EU, European Union

No respondents reported receiving psychoeducation/self help;  
psychotherapy/self help; psychotherapy/psychoeducation; psychoeducation

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria;  
GAMIAN/ P. Arteil, personal communication

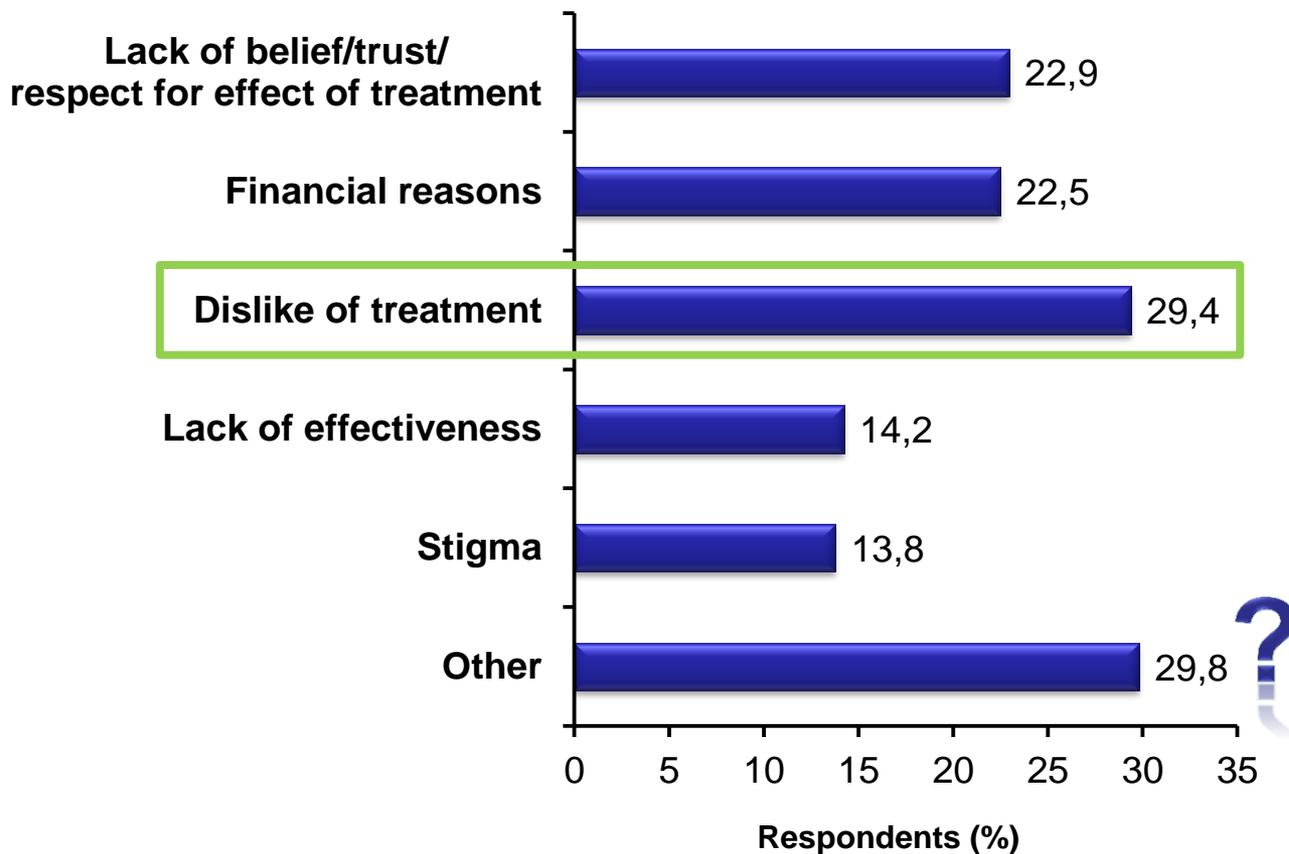
# Reasons for not currently taking medication or having stopped medication



The most commonly specified reason for medication non-adherence was side effects (31%)

Although 42% of patients selected other unspecified reasons

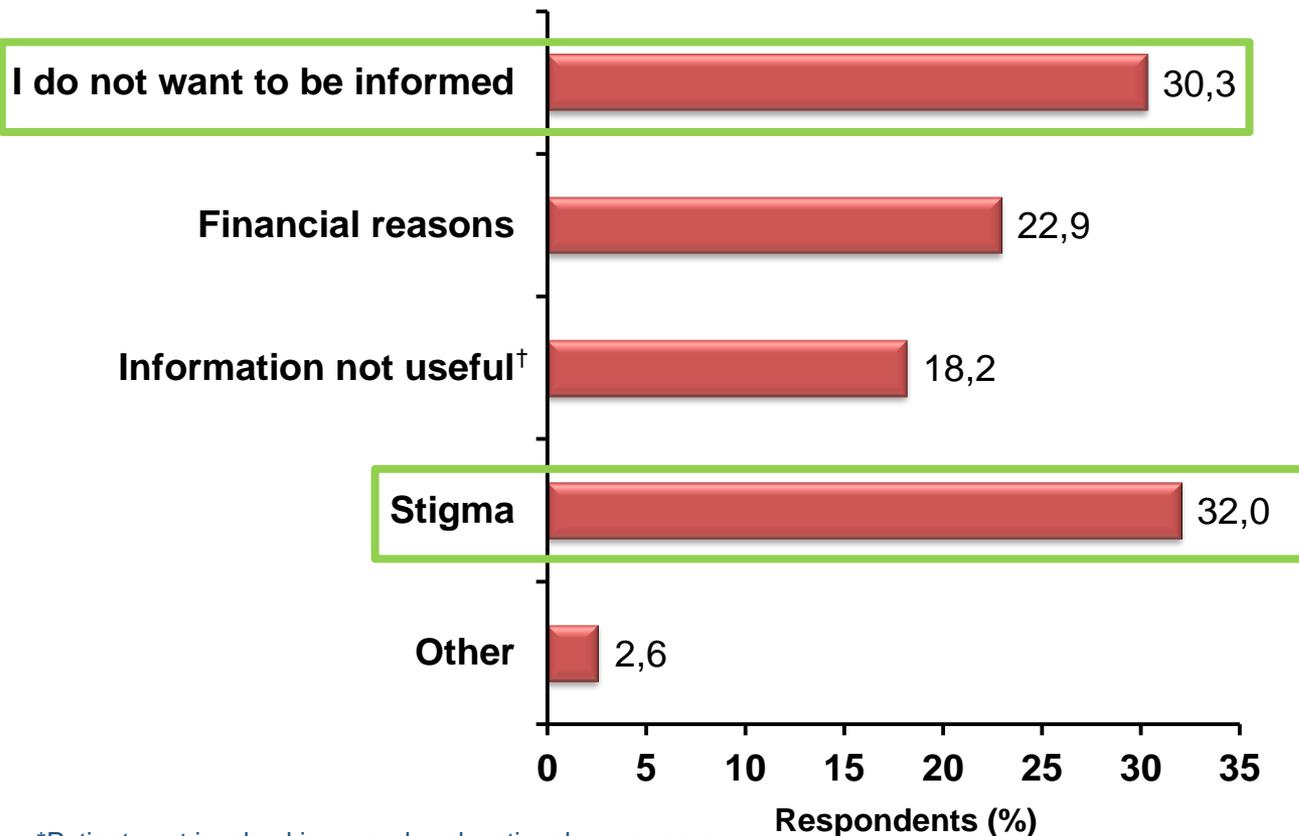
# Reasons for not attending or having stopped getting psychotherapy



Dislike of treatment was the most commonly specified reason for not attending or having stopped psychotherapy

Although 29.8% of patients selected other unspecified reasons

# Reasons for not attending psychoeducation\*



Of patients not involved in psychoeducation embarrassment to disclose their illness and not wanting to be informed were the most commonly specified reason for not attending or having stopped psychoeducation

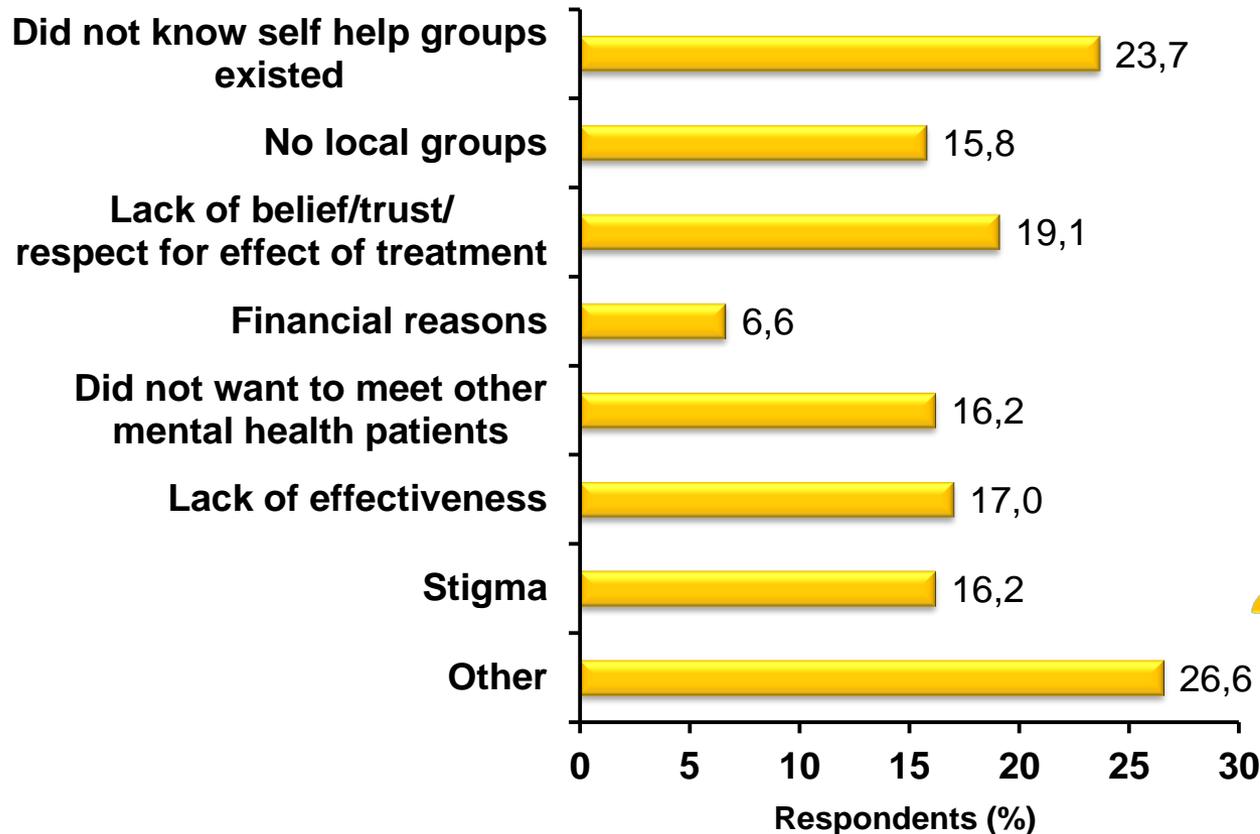
\*Patients not involved in a psychoeducational programme

†Information not useful for me; it was not adapted to my skills

Patients could select more than one option

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria

# Reasons for not attending self help\*



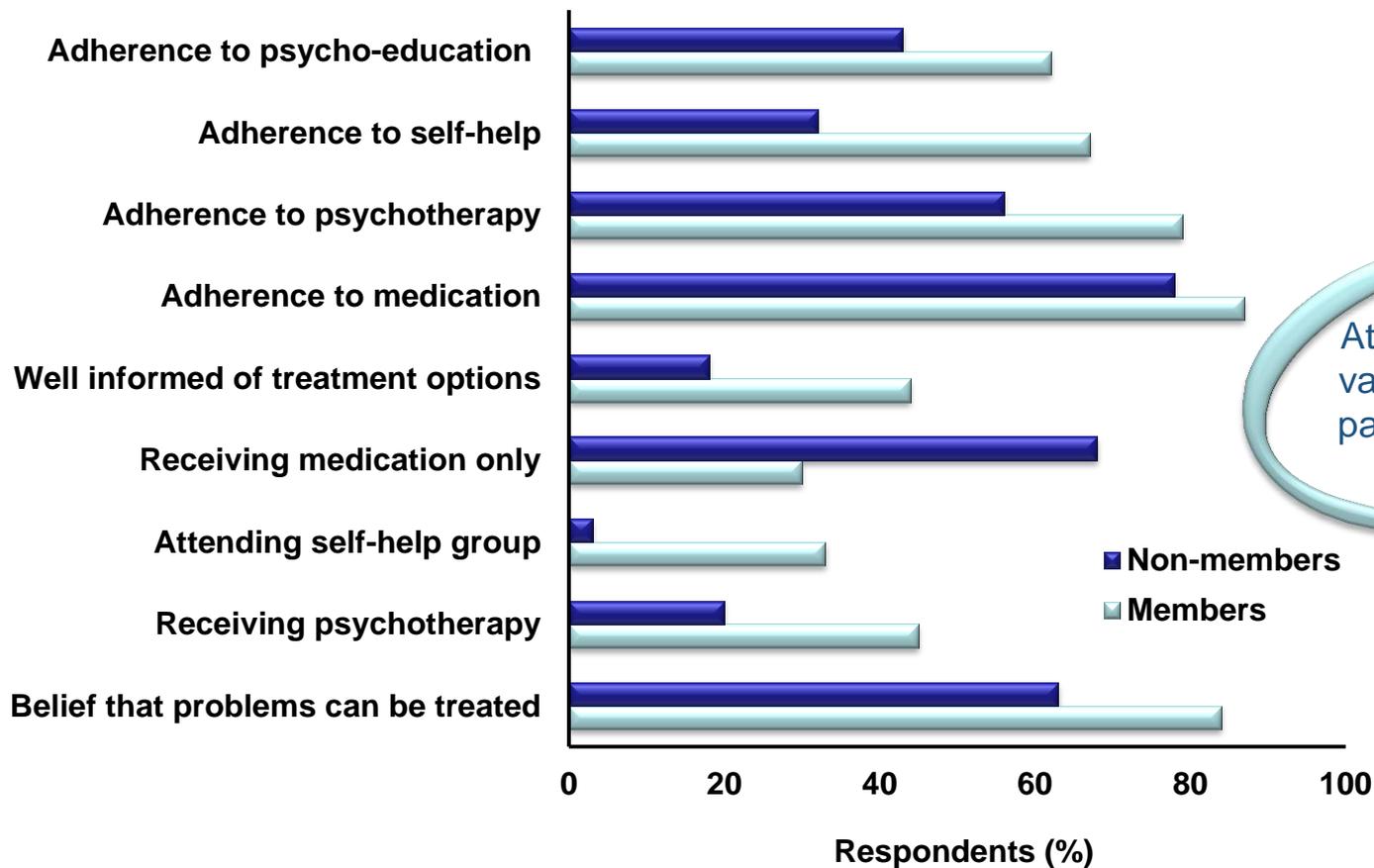
A considerable proportion of patients were not aware of self help groups

Although 27% did not attend for other, unspecified reasons

\*Patients who did not attend meetings of a self help group  
Patients could select more than one option

# **Role of patient organization**

# Members of patient associations tend to have more positive attitudes towards treatment

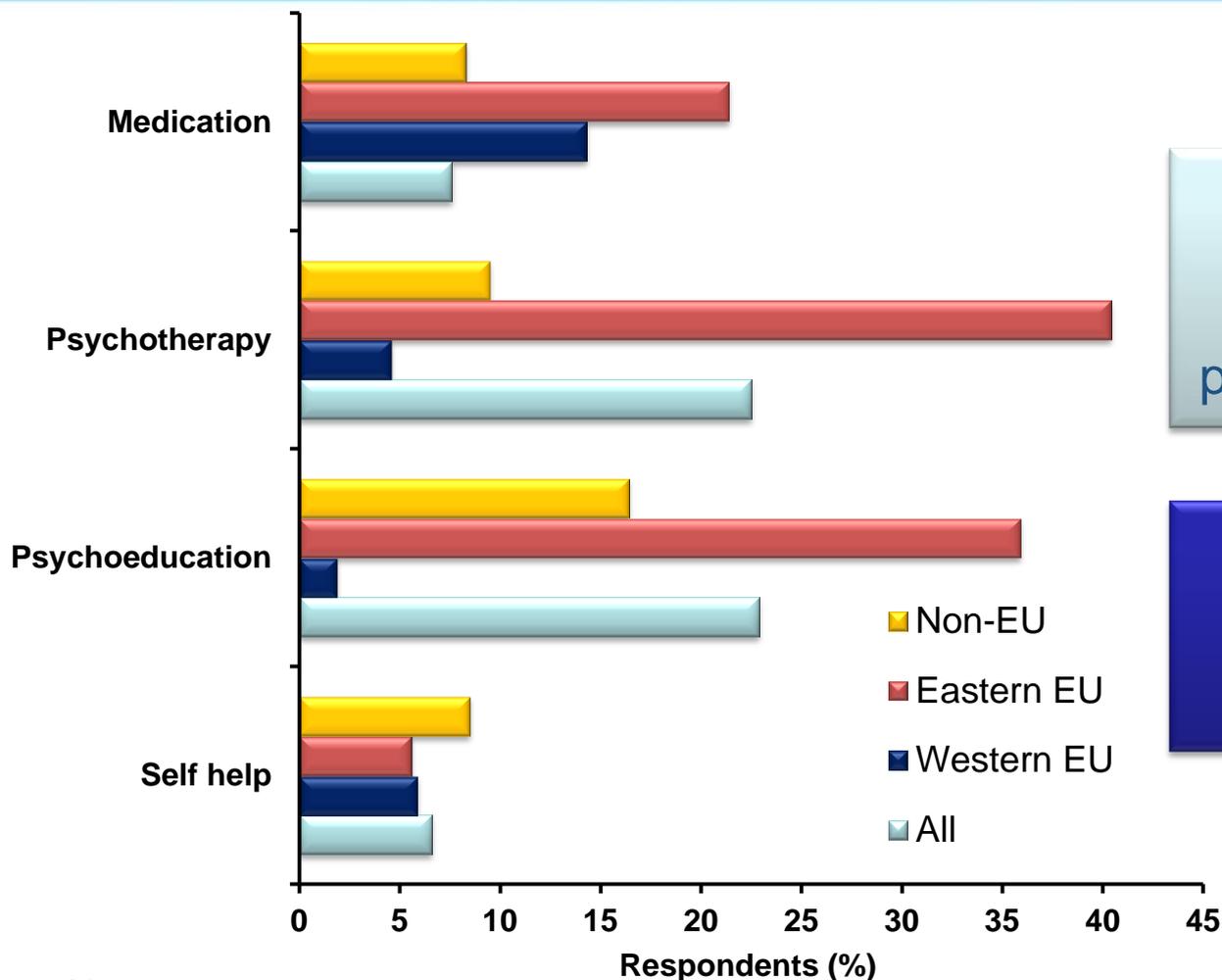


Attitudes towards treatment varied according to whether patients were members of a patients' association



# **Financial impact on adherence to treatment**

# Patients believe that financial barriers effect their attendance to treatment



Patients financial constraints impacted psychotherapy and psychoeducation the most

These constraints were greatest in Eastern European countries

Q/ Is there a financial barrier to attend treatment:

for financial reasons (it's too expensive, I cannot afford it)? Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria

Summary of key findings

# Conclusions

# Conclusions (1)

Adherence to treatment covers more aspects than antipsychotic medication alone, however:

- Few respondents received medication in combination with other therapies
- Many patients were not well informed about treatment options

Families play an important role in the lives of patients with schizophrenia

- Patient care and treatment adherence are shared responsibilities

Many patients face financial barriers to accessing all forms of treatment

- There is an additional pressure of the financial crisis, particularly in Eastern European countries

# Conclusions (2)

Patient associations have an important and often underestimated role in managing schizophrenia

- They can help engage patients in treatment and encourage adherence

Members of patient organizations surveyed

- Had a better understanding of treatment choices available
- Were more positive towards treatment
- Were more likely to receive optimal care in line with current treatment guidelines<sup>1</sup>



**Thank you**

**<http://www.gamian.eu>**