Adherence to treatment:

The patient's view

GAMIAN Europe 2012

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Advocacy Networks

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Gamian-Europe: presentation

GAMIAN-Europe[1] was established in 1998 as a representative coalition of patient organisations. Putting the patient at the centre of all issues of the EU healthcare debate, the organisation aims to bring together and support the development and policy influencing capacity of local, regional and national organizations active in the field of mental health.
Patients can and should play an effective and complementary role in developing positive and pro-active policies and other initiatives with an impact on mental health issues. GAMIAN-Europe, as an informed and effective advocate, is seeking to become a powerful and trusted point of reference for the main EU institutions and other organisations and stakeholders seeking the views of patients.

GAMIAN-Europe's main objectives:

Advocacy

- Act as the voice for patients, both at EU as well as at national level, and demonstrate that this voice is useful as well as indispensable
- Ensure that patients are at the centre of all aspects of healthcare provision
- Work to improve the availability, accessibility, and quality of treatment for all mental health problems

Information and education

- Improve the provision, reliability and quality of information on mental health problems for patients as well as the general public
- Assist in improving the training, education and understanding of mental illness of health and other professionals

Stigma and discrimination

- Increase awareness, knowledge and understanding of mental health problems

[1] ***Board of Directors:***
***President*: Dolores Gauci (Malta), *Immediate Past President:* Raluca Nica (Romania),**
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- Help reduce stigma, prejudice, and ignorance in relation to mental health problems and fight discrimination

Patients' rights

- Focus on the development and enforcement of rights for persons affected by mental health problems, e.g. access to appropriate treatment

Cooperation, partnerships and capacity building

- Enable patient groups to collaborate with health professionals, policy makers, academics, and industry

GAMIAN-Europe's activities:

In order to reach these aims, GAMIAN-Europe

- provides information and support to member organisations by means of educational seminars, conventions, a regular EU newsletter, handbooks on specific mental illnesses, and an up-to-date and accessible website.
- facilitates an open and inclusive pan-European dialogue among patient organisations and other interested bodies to exchange information and ideas.
- shares experience and examples of good practice to strengthen the role and voice of patient organisations and effective input in EU and national policy development.
- forms active partnerships and cooperation with other stakeholders, e.g. the media, organisations (local, regional, national, European and academic institutions), employers and trade unions, the pharmaceutical industry, government and regulatory bodies and insurers with a view to
  - securing the best possible treatment for patients with a mental illness and at the earliest possible opportunity
  - supporting the development of health/mental health policies which take account of the views of patients

Gamian Questionnaires, a user run initiative

GAMIAN-Europe wishes to contribute to an open and innovative reflection process, in order to advocate the need to address health in a holistic fashion and the development of care and support facilities and services for people with mental health problems.

To this effect, GAMIAN-Europe stimulate international cooperation and awareness raising on important topics , for instance by means of the European Interest Group on Mental Health, Well-being and Brains Disorders, to which GAMIAN-Europe provides the secretariat.

Aiming to speak up for patients, GAMIAN-Europe organizes since 2006 regular consultations of its membership (through national patient associations in most European countries:

Stigma Survey - project developed by GAMIAN Europe in 2006.

In 2006 GAMIAN-Europe undertook an extensive pan-European survey involving twenty countries across geographical Europe with a meaningful spread to involve countries from Eastern, Central, Western, Northern and Southern Europe utilising our extensive organisation's membership in those countries.

In 2010 the questionnaire was submitted again, to see if there has been any evolution in the last 5 years.

The results were presented at the EU conference on stigma in Lisbon (November 2010) and at the MEP interest group (3rd May 2011)

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In 2011 a second survey was set up on the physical health problems of people suffering from mental health problems

Gamian-Europe and the adherence to treatment.

Gamian-Europe has adopted the WHO[2] definition of adherence to long-term therapy:
the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.

It is important to differentiate "adherence" from "compliance". The main difference is that adherence requires the patient's agreement to the recommendations.

GAMIAN believes that patients should be active partners with health professionals in their own care and that good communication between patient and health professional is a must for an effective clinical practice.

Adherence to treatment is more than adherence to medication: a holistic view on treatment:

Gamian-Europe believes there are four cornerstones to the treatment of persons with mental health problems:
Each patient will need to work together with the psychiatrist and healthcare team to determine what combination works best for him/her. Gamian-Europe considers that it is likely that the best package of care will include elements of each of these four types of treatment.

- **Medication**
  Antipsychotic medication is widely recommended as first-line treatment for persons with schizophrenia experiencing their first acute positive symptom episode

- **Psychotherapy/Counselling**
  Although antipsychotic medications **are** the mainstay of treatment for schizophrenia, pharmacotherapy alone produces only limited improvement in negative symptoms, cognitive function, social functioning and quality of life. Additionally, many patients continue to suffer from persistent positive symptoms and relapses particularly when they fail to adhere to prescribed medications. This underlines the need for multi-modal care including psychosocial therapies as adjuncts to antipsychotic medications to help alleviate symptoms and **to improve adherence**, social functioning and quality of life. (Schizophrenia Research 122 (2010) 1-23 Schizophrenia, "Just the Facts" 5. Treatment and prevention Past, present, and future, Rajiv Tandon, Henry A. Nasrallah, Matcheri S. Keshavan)

- **Psycho-education** The more a patient learns about his/her condition the better placed he/she will be to take control of it. Psycho-education uses this principle within a clearly defined therapeutic programme in which a trained therapist delivers targeted information that is designed to reduce both the frequency and the severity of your symptoms. Psycho-education should be an integral part of an overall treatment plan. It will increase knowledge and understanding of the illness and treatment and help to cope more effectively. It may also help the patient to keep taking medication. Many people find that they benefit not only from the information they receive during psycho-education, but also from the learning process itself. There are several different ways in

[2] WHO. Adherence to long-term therapies. Evidence for action, 2003

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which psycho-education can be delivered. These include one-to-one sessions with a therapist, sessions aimed specifically at carers and family members, group sessions attended by several people with a mental disorder and mixed group sessions attended by a number of people with a mental disorder and members of their family. A course of psycho-education should include a series of sessions over a period of months or even years.
Lin et al. reported that patients were more likely to **continue to take their medication** during the first month of treatment if they had received specific educational messages, namely that they should take their medication daily, that they might notice no benefit for the first 2–4 weeks, that they should continue even if they felt better and that they should not stop medication without consulting their doctor. They also received advice about how to seek answers to questions about medication (14). The impact of such advice has not been evaluated prospectively.

- **Self-help**. Self-help groups offer a voice with the time to listen to patients' concerns, their side-effects, their self-doubt, and that can reassure them **and improve adherence** – often from first-hand experience, for example, that the side-effects they are experiencing are transient, normal and non-threatening and will usually disappear in time. The only real experts on living with a mental disorder are those who are already doing so. As a result, most support groups are full of people who can share how they have managed to cope and move on with their lives. They may be able to deal with questions themselves or know where to go to find the answers. Many support groups have used this expertise to produce helpful information in leaflets, videos and on websites.

> *If we do not have a Health care system that is supportive of the users, adherence will be low. Poor, inadequate or even harmful interventions are causing non-adherence. If patients are denied their basic fundamental rights, they cannot be adherent*
> (Aikaterini, Greece)

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A survey on Adherence to Treatment.
The adherence to treatment Online Questionnaire (2012)

Background

- The Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe), a representative coalition of patient organizations, advocates that the best package of care for the treatment of people with mental health problems include elements of medication, psychotherapy/counselling, psychoeducation and self-help
- This view is consistent with current guidelines for the treatment of patients with schizophrenia that recommend the integration of pharmacological and psychosocial treatments for optimal long-term patient outcomes1
- However, failure to take medication as prescribed is common amongst patients with schizophrenia,2 with patients frequently forgetting to take medication and/or actively deciding not to take it3
- The consequences of partial- and non-adherence to medication can include an increased likelihood of experiencing residual symptoms and functional impairments as well as an increased risk of relapse and re-hospitalization4
- In considering the impact of partial- or non-adherence, it is important also to consider it in a wider context than simply taking antipsychotic medication as prescribed
- Moreover, understanding the reasons for poor adherence in patients with schizophrenia from a patient perspective may help to identify ways to address this issue more effectively

Methods

- A survey of a European sample of patients with a diagnosis of schizophrenia, aged 18 years or older, was conducted in different countries to assess their experiences particularly in relation to adherence to medication, psychotherapy/counselling, psycho-education programmes and self-help initiatives
- The survey was conducted via a questionnaire comprising 23 questions including the demographics of respondents
- The questionnaire was compiled by a steering committee consisting of patient representatives and academics

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- Surveys were translated into 20 languages to ensure the questions were readily understood by all participants. Participants could respond in their own language
- The survey was made available online but for those participants who did not wish to respond online a printed version could be downloaded and returned to GAMIAN-Europe by post
- The survey was active from 1 April to 14 July 2012
- The surveys were completed anonymously; no individual patient data were collected
- Completed surveys were returned to GAMIAN-Europe for data analysis

Results

Demographics of respondents

- 403 responses were received from respondents in 18 countries*
- The demographics of the respondents are shown in Table 1
- 63% of respondents were aged 31–50 years
- 44% of respondents live with parents or relatives
- 49% of the respondents were diagnosed over ten years ago
- 90% of the respondents have been hospitalized for their schizophrenia at some time since their diagnosis
    - 42% had been hospitalized five times or more
    - 38% have been hospitalized for up to 6 months

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Table 1. Demographics of participants (n=403)

Gender	%
Male	63
Age (years)	%
18–30	15.14
31–50	63.03
51–70	20.35
>70	1.49
Living arrangements	%
Alone	21.09
With spouse/partner	17.12
With children	4.22
With parents/relatives	43.67
With friends	0.99
With roommates	8.44
Other	4.47
Time since diagnosis	%
<2 years	9.43
Between 2 and 5 years	14.89
Between 5 and 10 years	27.30
More than 10 years	48.39
Type of treatment	%
Medication	85.36
Psychotherapy	26.30
Psycho education	12.90
Self-help	13.65
None	2.98
Frequency of hospitalization	%
Never	6.70
Once	19.11
2–4 times	31.76
5–10 times	23.82
>10 times	18.36
Duration of hospitalization	%
Never	6.70
<1 month	13.65
1–6 months	40.94
6–12 months	13.90

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>12 months	24.32

Attitude to disease

- There is a high level of acceptance of the diagnosis amongst respondents (63% agreed with their diagnosis) and 74% of respondents believed that their problems can be treated

Treatment for schizophrenia

- Most respondents were receiving antipsychotic medication (85%); 26% received psychotherapy; 13% participated in a psycho-education programme and 14% were members of a self-help group (Table 1)
- 34% of respondents received medication along with another form of psychosocial therapy (either psychotherapy, psycho-education or self-help) (Figure 1)
- Antipsychotic medication was the only form of therapy for 52% of respondents
    - Oral medication was the most common form of antipsychotic treatment, with 55% of respondents having received this form of medication
    - 11% of respondents had previously, or were currently, receiving long-acting medication

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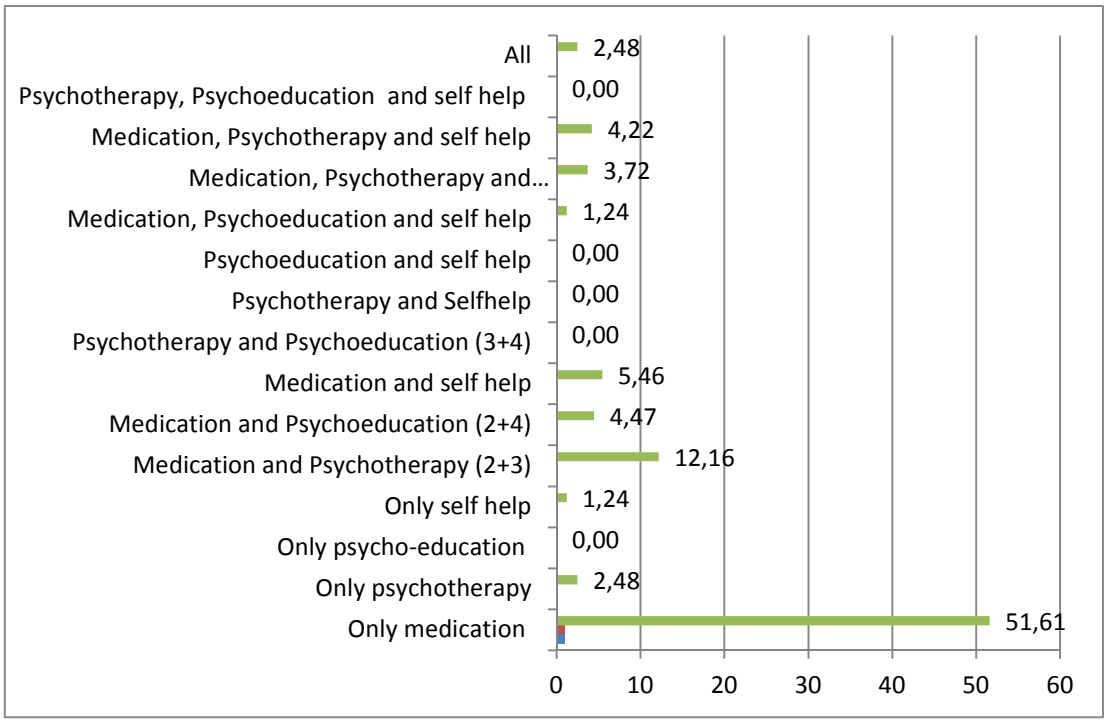
Figure 1. Combination of treatments

Only medication (2)	208	51,61%
Only psychotherapy (3)	10	2,48%
Only psycho-education (4)	0	0,00%
Only self help (5)	5	1,24%
Medication and Psychotherapy (2+3)	49	12,16%
Medication and Psychoeducation (2+4)	18	4,47%
Medication and self help (2+5)	22	5,46%
Psychotherapy and Psychoeducation (3+4)	0	0,00%
Psychotherapy and Selfhelp (3+5)	0	0,00%
Psychoeducation and self help (4+5)	0	0,00%
Medication, Psychoeducation and self help (2+4+5)	5	1,24%
Medication, Psychotherapy and Psychoeducation (2+3+4)	15	3,72%
Medication, Psychotherapy and self help (2+3+5)	17	4,22%
Psychotherapy, Psychoeducation and self help (3+4+5)	0	0,00%
All (2+3+4+5)	10	2,48%



Attitudes to treatment: general

- 49% of respondents considered that they were well informed on possible treatment options. 37% did not consider themselves well informed (Figure 2)

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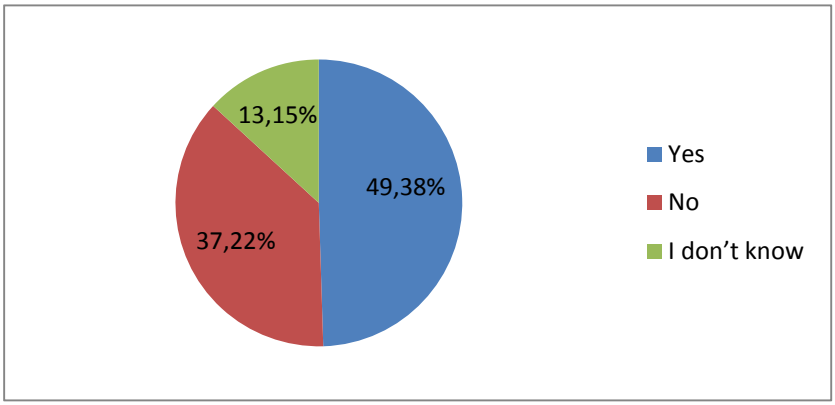
Figure 2. Patients perception of their awareness of possible treatment options

☐ 1.Yes	199	49,38%
☐ 2.No	150	37,22%
☐ 3.I don't know	53	13,15%



- The majority of respondents believed it was important always to take treatment exactly as prescribed by the doctor; however, the responses varied according to the type of treatment (Figure 3)

Figure 3. Perceptions of the importance of always taking treatment exactly as prescribed by the doctor

Selfhelp (n=182)

☐ 1.Yes	96	52,75%
☐ 2.No	36	19,78%
☐ 3.I don't know	50	27,47%

Psycho-education (n=159)

☐ 1.Yes	81	50,94%
☐ 2.No	31	19,50%
☐ 3.I don't know	47	29,56%

Psychotherapy (n= 217)

☐ 1.Yes	148	68,20%
☐ 2.No	19	8,76%
☐ 3.I don't know	50	23,04%

Medication (n= 391)

☐ 1.Yes	323	82,61%

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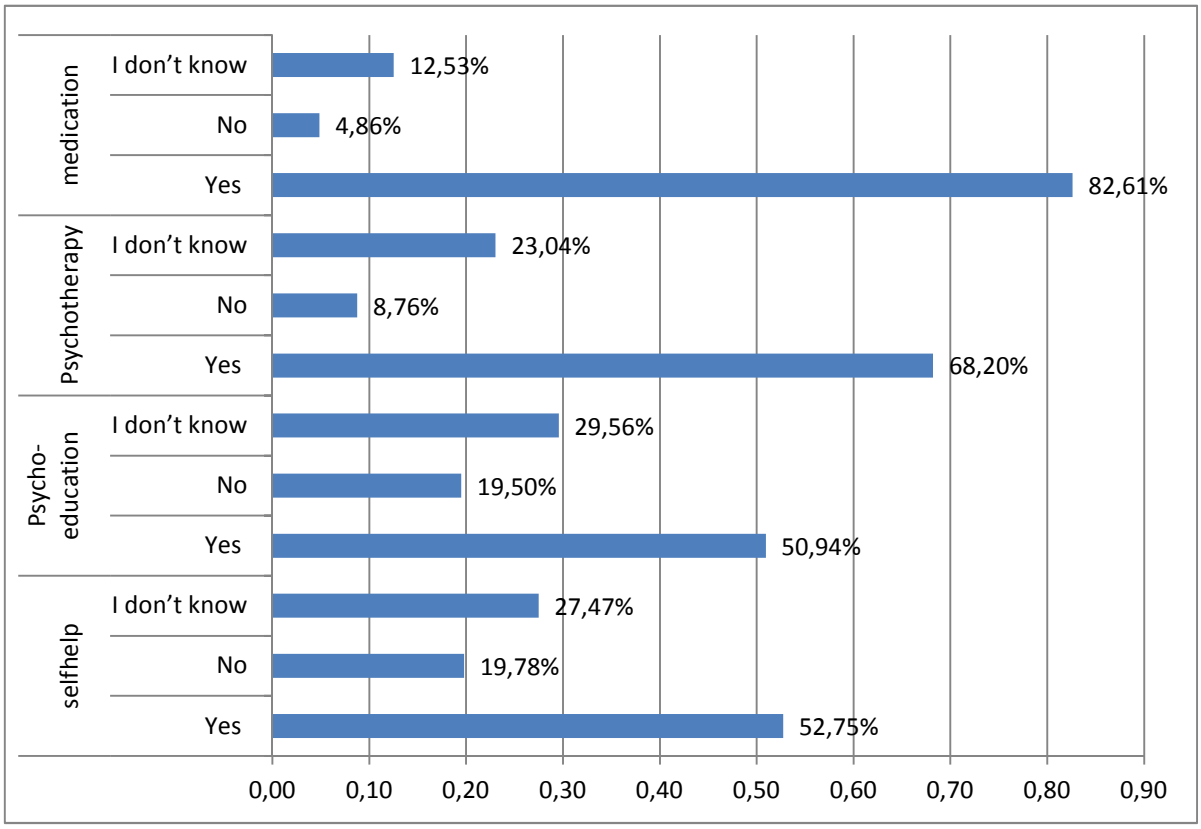
☐ 2.No	19	4,86%
☐ 3.I don't know	49	12,53%



- 33% of respondents stated that they relied upon other people, such as family and friends, to remind them to take their medication or to attend psychosocial treatment sessions (psychotherapy [28.50%], psycho-education [32%], self-help [27%])
- Respondents who were members of a patient association were more positive towards treatment, were better informed about treatment options, were more likely to adhere to treatments and were also likely to receive better treatment (ie combination of medication and psychosocial therapy) (Figure 4)

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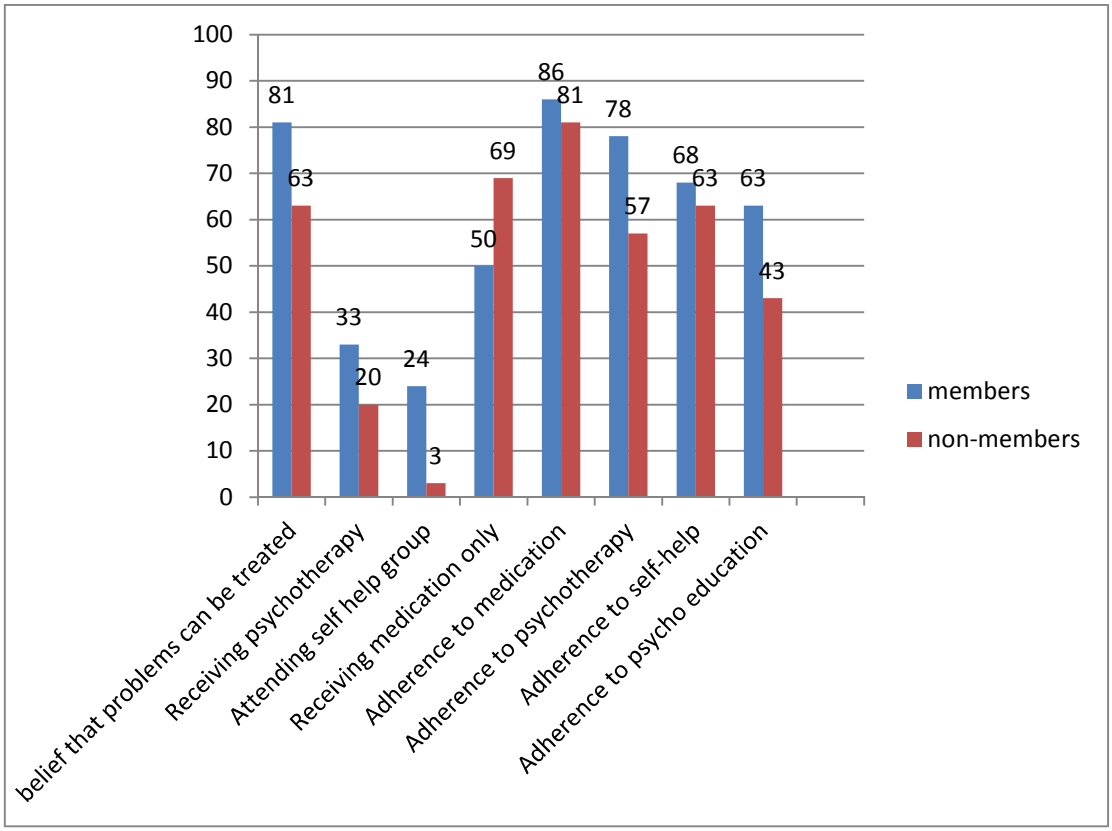
Figure 4. Comparison of attitudes between respondents who were members of patient associations with those who were not members



Attitudes to adherence: medication

- Apart from unspecified reasons, the most common reasons for medication non-adherence amongst respondents were side effects (33%) and lack of belief/trust/respect for the treatment (14%) (Table 2)
    - Financial reasons were the least frequently cited reason for non-adherence (8%)
- 67.50% of respondents considered that a medication that only had to be taken once a month was preferable to their current medication (Figure 5)
- 24% of respondents felt that they were considered 'crazy' by their acquaintances for taking medication

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Table 2. Reasons for not attending treatment or having stopped treatment**

	Medication (n=144)	Psychotherapy (n=217)	Psycho-education (n=231)	Self help (n=241)
Reason	**%**	**%**	**%**	**%**
Lack of awareness of treatment	NA	NA	NA	23.7
Lack of access	NA	NA	NA	15.8
Lack of belief/trust/respect for effect of treatment	18.9	22.9	NA	19.1
Dislike of treatment	13.1	29.4	30.3	16.2
Side effects	32.85	NA	NA	NA
Lack of effectiveness	13.9	14.2	18.2	17.0
Stigma	17.5	13.8	32.0	16.2
Other	44.3	29.8	2.6	26.6

- **Not attending treatment includes not taking medication, getting psychotherapy, receiving psycho-education or going to a self-help group.
- NA, not applicable

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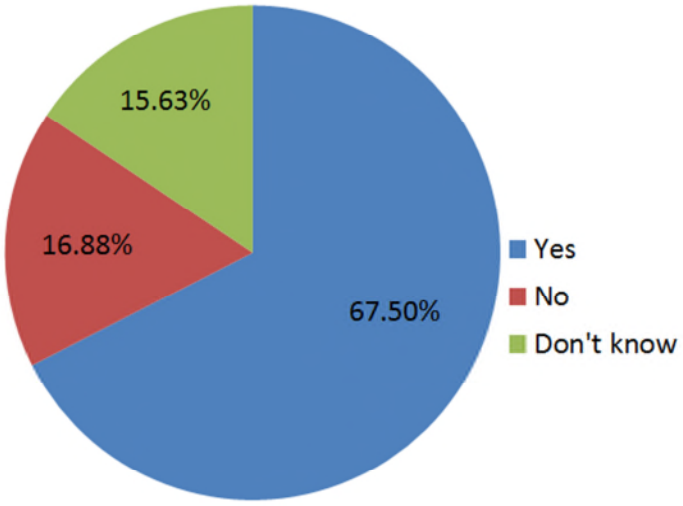
Figure 5. Respondents' preference to take a medication once a month



Attitudes to adherence: psychotherapy/counselling

- Disliking the treatment (29%), lack of belief/trust/respect for the treatment (23%) and financial reasons (22%) were the most common reasons for non-adherence to psychotherapy/counselling amongst respondents

Attitudes to adherence: psychoeducation

- Respondents reported that stigma (32%) was the most common reason for not attending psychoeducation programmes. Not wanting to be informed (30%) and financial reasons (23%) were also frequently reported reasons (Table 2)
    - Fewer patients (18%) did not adhere to psycho education due to it not being adapted to their individual's skills and therefore being considered not useful

Attitudes to adherence: self-help

- The most common reasons for not attending self-help groups were lack of awareness of the existence of such groups (24%) and lack of belief/trust/respect in the type of treatment (20%) (Table 2)
    - Financial reasons (7%) were infrequently recorded as reasons for not attending self-help groups

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Factors affecting adherence to treatment

- There is a financial barrier for patients in attend to all forms of treatment, with this factor having the greatest impact on psychotherapy and psycho education. The financial constraints are greater in Eastern European countries than other regions (Table 2)
    - Specifically, respondents in Greece were less likely to receive adequate therapy (medication and psychosocial therapy) due to financial constraints

Conclusions

- Adherence to treatment covers broader aspects than medication alone. Psychotherapy, psychoeducation and self-help sessions should also be considered part of the holistic treatment for people with schizophrenia
- However, this survey highlights that relatively fewer patients received medication in combination with psychotherapy than those who received medication alone
- Repeated hospitalization was common for respondents to the survey (almost half of all respondents having been hospitalized more than five times); however, early diagnosis and access to treatment has been shown to have a positive impact on patient outcomes and save healthcare resources and costs5,6
- Patient associations have an important role in the management of schizophrenia and the support of patient associations can be very effective in strategies to engage in treatment and support adherence
- In particular, this survey highlights that members of patient organizations have a better understanding of the treatment choices available, are more positive towards treatment and are more likely to receive optimal care in line with current treatment guidelines1
- Nevertheless a considerable proportion of respondents to the survey do not consider themselves to be well informed about treatment options
- In addition, families have a particularly important role in the care of people with schizophrenia. In this survey, one third of respondents are living with their family and about one third rely on family and friends to remind them to take their medication
- Patients in many countries face significant financial barriers to all forms of treatment with the greatest impact seen on countries facing the greatest economic pressures

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Footnotes:

*Participating countries

Western EU: Belgium, France, Italy, Netherlands, UK, Malta; Eastern EU: Poland, Slovenia, Czech Republic, Hungary, Lithuania, Romania, Greece; Non-EU: Croatia, Russia, Turkey, Israel; Non Europe:

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